RHEUMATIC CONDITIONS IN THE NORTHERN PART OF CENTRAL JAVA

AN EPIDEMIOLOGICAL SURVEY

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AN EPIDEMIOLOGICAL SURVEY

REUMATISCHE AANDOENINGEN IN HET NOORDELIJK GEDEELTE VAN MIDDEN JAVA

EEN EPIDEMIOLOGISCH ONDERZOEK

PROEFSCHRIFT

TER VERKRIJGING VAN DE GRAAD VAN DOCTOR
AAN DE ERASMUS UNIVERSITEIT ROTTERDAM
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JOHANNES DARMAWAN

GEBOREN TE PONTIANAK
WEST KALIMANTAN
INDONESIA

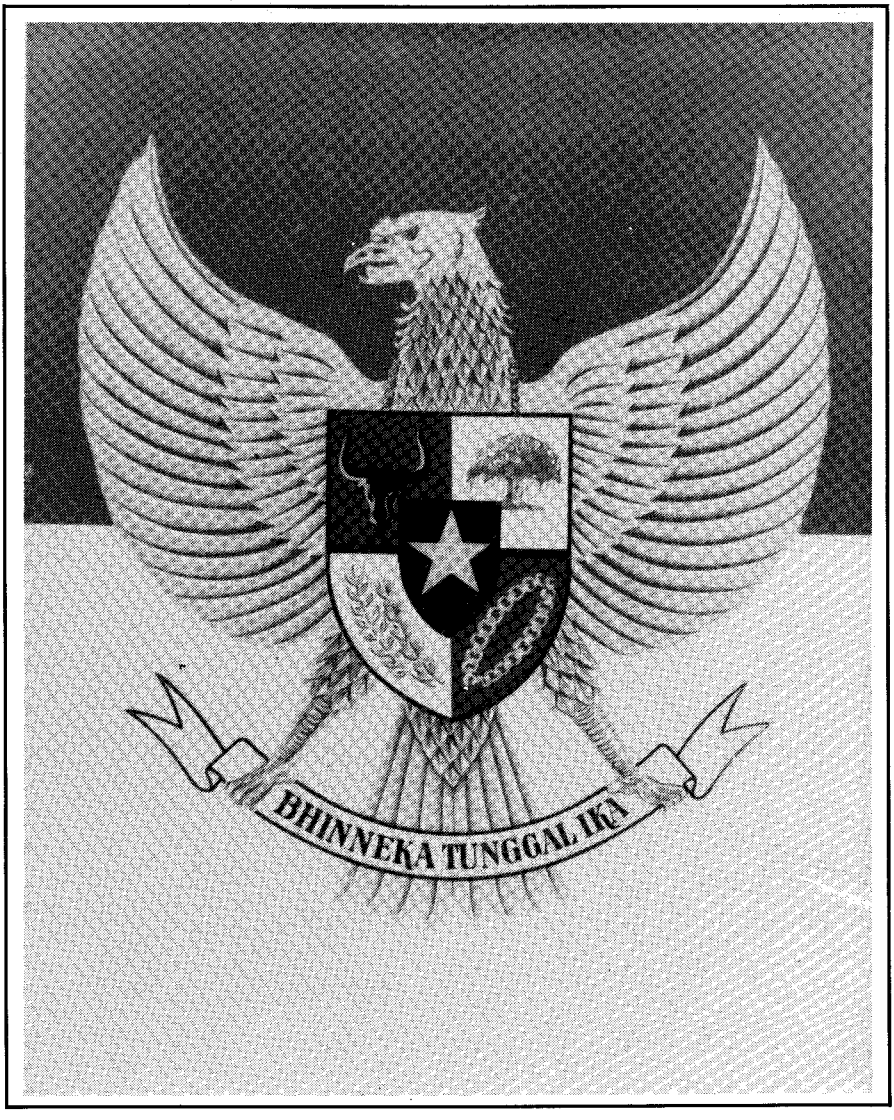
Promotiecommissie:

Promotor	:	Prof. Dr. H.A. Valkenburg
Overige leden:		Prof. Dr. A. Cats
		Prof. Dr. E. van der Does
		Prof. Dr. A.S. Muller

To my wife Lien

GARUDA PANCASILA

Indonesia's coat of arms is the Garuda Pancasila composed of the bird Garuda, the shield Pancasila and a two colours background of red on top of white with the motto "Bhineka Tunggal Ika". Bhineka Tunggal Ika means Unity in Diversity, signifying the unity of the people in spite of their diversified ethnic and cultural origin. The background of red on top of white is the Sang Saka Merah Putih, the national flag. The five emblems depicted in the shield represent the national philosophy of Pancasila which is included in the Preamble of the 1945 Constitution. The five principles expounded in the national philosophy are: Belief in the One Supreme God (golden star); Just and Civilized Humanity (golden chain); Unity of the Nation (banyan tree); the People's Sovereignty guided by the wisdom of unanimity in deliberations among representatives (buffalo head); and Social Justice (rice and cotton plant).
Garuda is the eagle of ancient Indonesian mythology symbolizing creative energy.
The 1945 Constitution and Pancasila guide all the policies of the present government and the organ of state to attain its basic aims of: the setting up of a government which shall protect the people and defend the country; to increase the general welfare of the people; to develop the intellectual life of the nation; and to contribute towards the establishment of a world order based on freedom, peace and social justice.



The national symbol of Indonesia: The Garuda Pancasila.

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INTRODUCTION

During my training at the Department of Rheumatology, the Royal Melbourne Hospital, Australia in 1980 - 1981, Dr. Kenneth D. Muirden, one day mentioned that in the Philippines a phase one COPCORD population survey was performed under the direct supervision of Dr. Lourdes Manahan, the local resource person. At that time I had not the faintest idea what COPCORD and resource person stood for.

Back in Semarang, Central Java, Indonesia, I started recording rheumatic diseases as these were seen at the Seroja Arthritis Center from the second of January to the end of December 1982. The major diagnostic categories encountered were degenerative conditions and soft tissue or extra-articular rheumatism. Rheumatoid arthritis was relatively uncommon, although it could be as severe as seen in Melbourne, Australia. Corticosteroid abuse apparently constituted a problem as this drug was available over the counter of ordinary shops in mixtures with phenylbutazon or herbal medicines either in capsule or tablet form (0.1).

Data on rheumatic diseases in the developing countries are scarce and conventional epidemiological surveys are considered too expensive and unlikely to succeed in third world countries lacking skilled manpower.

In the seventies a number of discussions took place between the World Health Organisation (WHO) and the International League Against Rheumatism (ILAR) with the objective to develop an epidemiological method which at a low cost would provide data on the magnitude of rheumatic problems. From these discussions the Community Oriented Programme for the Control Of Rheumatic Diseases (COPCORD) emerged and its feasibility was tested in a pilot project in a rural area in the Philippines. As a WHO-ILAR joint venture the Community Oriented Programme for the Control Of Rheumatic Diseases has been developed in particular for developing countries with emphasis on rural populations which make up two-thirds of the world population. It consists of three stages. In stage one epidemiological data are collected. In stage two, education of paramedical and medical professionals in the existing primary health care system is provided for. Stage three

deals with the improvement of the health care for those who have a perceived need for treatment of their rheumatic disease (0.2). In the COPCORD principle the modality of data collection on rheumatic complaints and perceived need for treatment is performed by local personnel of the existing health care system by means of simple questionnaires. It is therefore inexpensive (0.3).

After the COPCORD phase one study in the Phillippines was completed it was contemplated to perform a similar population survey in another developing country. Next to a search for musculoskeletal complaints, disability and perceived need for treatment the identification of possible risk factors was considered. The author was asked to be the resource person for this study and given to understand that no research funds were available from the WHO and the ILAR. Fortunately one local pharmaceutical company agreed to support the first phase of the Indonesian rural COPCORD population survey. The subsequent phases were financed from various resources.

A short general outline on Indonesia and in particular the island of Java with emphasis on Central Java is presented in chapter I with more details on the rural Subdistrict of Bandungan where the population research was completed.

Chapter II elaborates on the why of the COPCORD and its ultimate development.

The how and circumstances of the Indonesian COPCORD execution are discussed in chapter III under the heading of population and methods, including radiological and serological methods (the author's subjective impression of the weal and woe of the study is described in appendix 7 in the form of a diary).

The results of the study i.e. the response rates in the various phases are presented in chapter IV. The complaint and disability rates, and the utilization of the official and traditional primary health care services are discussed in chapter V. The disease categories diagnosed, serology and X-ray assessment are discussed in separate chapters. Rheumatoid arthritis in chapter VI is followed by spinal degenerative and other conditions in chapter VII. Chapter VIII gives a description of osteoarthritis of the peripheral joints. Extra-articular rheumatism is reported in chapter IX, gout in chapter X, while

chapter XI contains various miscellaneous rheumatic conditions. Chapter XII concludes the thesis with a reappraisal of the COPCORD principle and recommendations for improvement of the design and future research.

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CHAPTER I
THE LAND AND THE PEOPLE

1.0 Indonesia

The name Indonesia first used by the British ethnologist G.R.Logan in 1850 is derived from the Latin "India" and the Greek "Nesos". India Nesos means Indian Islands or Indian Archipelago (1.1).

1.0.1 *Geography*

Indonesia is the largest country in south-east Asia, both in population and land area. Its strategic location across two continents, two oceans and important trade routes has shaped its history. Surrounded by mainland Asia and Australia, the Pacific and Indian Ocean, its boundaries are north: Andaman Sea, Strait Malacca, South China Sea, East Malaysia (Malaysian Borneo), Celebes Sea, Pacific Ocean; east: Papua New Guinea; south: Arafura Sea; west: Indian Ocean.

Indonesia is situated between latitudes 6 degrees North and 11 degrees South and longitudes 95 degrees West and 141 degrees East. The Indonesian archipelago of 13,677 islands stretches in a rough crescent for 5,500 km from the Malay peninsula eastward to the Philippines and Australia. The land area is 1,905,443 sq km (735,354 sq miles) and extend 5,152 km (3,200 miles) from east to west and 1,770 km (1,100 miles) from north to south.

The archipelago is divided into the Greater Sunda Complex comprising of Sumatra, Java, Kalimantan, Sulawesi; the Lesser Sundas (Nusa Tenggara), which extend from Bali to Timor and the Moluccas (Maluku) and thirdly Greater Irian (fig. 1.1).

The highest point is the snow covered summit of Mount Carstensz (Gunung Jaya Wijaya) in Irian Jaya which is 5,000 meters above sea level and the lowest point - much of coastal Kalimantan (Borneo)- is below sea level.

Climate

The Indonesian archipelago lies along the equator and the climate is tropical with a high humidity from 69 - 95%, slight changes in temperature and heavy rainfall. Temperature generally ranges from 20 - 30 centrigrades (68 - 86 degrees Fahrenheit) except at higher altitudes. Rainfall is heaviest along the equatorial belts between the months of November and February. The driest period is from June to September. Rainfall averages more than 102 cm annually, but most of Sumatra, Kalimantan, Central Sulawesi and the Moluccas are in the tropical rainbelt along the equator and have 200 - 250 cm of rainfall yearly.

Fauna and flora

In the ice-age Sumatra, Java and Kalimantan were joined together and shared the Sunda shelf with the Asian mainland and Irian Jaya laid on the Sahul shelf with Australia (1.2). Consequently Indonesia is divided into three zones. The zonal fauna shows similarities with one of the continents it belongs to, while the region in between composed of deep sea basins interspersed with island blocks has another type of fauna and even a marked difference in the flora.

Rare species are protected from extinction in sanctuaries throughout the country such as Orangutan primates in Sumatra and Kalimantan, the Komodo dragon (giant lizard) on the small islands off the west coast of Flores; one-horned rhinoceros in West Java; the Babirusa (pigdeer) and Anoa (dwarf bufalo) in Sulawesi (Celebes).

1.0.2 History

The fossils of Pithecanthropus Erectus (Java Man) discovered in 1890 in the vicinity of Trinil village, East Java, proved that Indonesia was inhabited more than 300,000 years ago (1.3). Artefacts excavated indicate early stone civilisation. Between 3,000 and 500 B.C. migration of Malaysians of Mongoloid heritage took place from South China, Junnan and Tonkin, which introduced New Stone, Bronze and Iron Age cultures and the Austronesian languages. The migrants mixed with the original inhabitants (probably Negritos), cultivated wet rice fields, engaged in animal husbandry and lived in villages. As seafarers with

knowledge of navigation they sailed as far west as Madagascar and east to Polynesia and the Easter Islands (1.4).

Trade was established with China from 206 to 24 B.C. In the first century A.D. contact was made with South India, which brought an influx of Hindus until the seventh century. Hindu and Buddhist influence lasted for fourteen centuries, in the process creating an Indonesian-Hindu civilisation. Two powerful kingdoms rose - Sriwijaya in Sumatra from the seventh to the ninth century and Majapahit in East Java in the tenth century. Majapahit disintegrated finally in the sixteenth century.

The Arabs first landed in North Sumatra in 846 A.D. and Moslem kingdoms emerged in Java in the sixteenth century thereby absorbing the crumbling Hindu realms and spreading Islam throughout the islands.

In search of spices the Portuguese arrived in the Spice Islands (Maluku) in the sixteenth century, followed by the United Dutch East India Company (VOC) in 1605 which got control of the spice and coffee trade by increasing their sovereignty over Indonesian territories.

Partial selfgovernment was introduced by Lieutenant Governor Thomas Stamford Raffles from 1811 to 1816 when during the Napoleonic war Holland was occupied by France and Indonesia fell under British East India Company rule. Countless uprising and liberation wars were waged and lost against the VOC with nationalistic sentiments growing and ultimately strengthened during the Japanese occupation which culminated in the proclamation of Indonesia's independence on August 17, 1945, by Soekarno and Hatta after the capitulation of Japan to the Allied Armed Forces.

1.0.3 The people

Indonesia is the fifth most populous country in the world, exceeded only by China, India, the Soviet Union and the United States of America. The country as a whole suffers not so much from overpopulation as from extremely uneven geographical distribution of people. The total population of more than 168 million (1984) is distributed over the archipelago with 65% of the total crowded onto the islands of Java and Madura, which cover only about 7% of the total land area of the country.

Although the population density is more than 700 per sq km here, many of the smaller islands are uninhabited and larger islands sparsely populated e.g. Sumatra which forms 25% of the nation's total land area has 16% of the country's population whereas Kalimantan which makes up 28% of the total land area has only a minuscule of 4% of the total population.

Population pressure will constitute Indonesia's most serious long-ranged problem on the islands of Java and Madura. Notwithstanding Indonesia is still an overwhelmingly agricultural country, urban population growth has been explosive since independence. The population of Jakarta, the country's capital, has grown from 533,000 in 1949 to more than 7.5 million now. Still 80% of the population lives in rural areas. Typically of developing countries, the population is predominantly young with 50% under the age of twenty years.

Indonesians are basically of Malayo-Polynesian racial heritage and are divided into approximately three hundred ethnic groups which speak about 365 languages and dialects. Except for the Papuan-based language of Eastern Indonesia, they belong to the Malayo-Polynesian language family. The largest groups are the Javanese, Sundanese and Madurese who live on Java and the neighbouring island of Madura. The coastal Malays, the Minangkabau, the Bataks and the Atjehnese are found on Sumatra. The Balinese and Makasar-Buginese are of the eastern archipelago. The Chinese are the largest non-Indonesian group followed by the Arabs and the Indians.

Indonesia's official language is Bahasa Indonesia derived from market Malay (Melayu Pasar) and lingua franca of the archipelago during the colonial period. The need for scientific, political and economic vocabularies led to the borrowing of many words from western languages, particularly from English and Dutch and invention of others by language committees. Concoctions from Indonesian and Malaysian language committees and the Javanese language spoken by the majority of people on Java continue to enrich its vocabulary. Finally it became a means of communication throughout the islands as the result of intensive government language training programmes, despite the fact that there are no native speakers of Bahasa Indonesia. Illiteracy is still high and exact figures are not available.

Eighty-five percent of the population are Moslems, though still strongly influenced by Hinduism, Buddhism, and older pagan and animistic beliefs. The remaining 15% are Hindus (almost entirely on the island of Bali), Protestants, Catholics (and other sects of Christianity), Buddhists and Animists (1.5).

1.0.4 The Government

The official name of the country is the Republic of Indonesia. The Head of State and Government is the President. Legislature is the House of Representatives (Dewan Perwakilan Rakyat) and Senate (Majelis Permusyawaratan Rakyat).

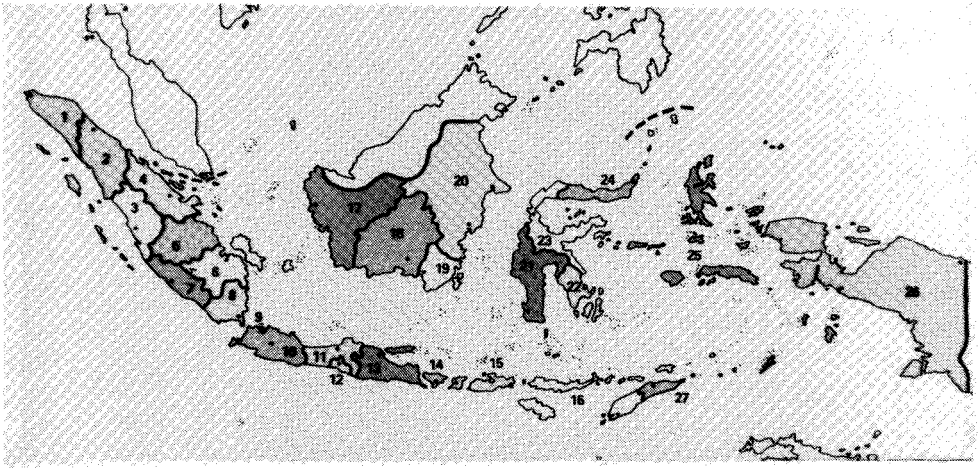

Fig. 1.1 The provinces of Indonesia
Central Java (11) lies in the middle of the island of Java.

Administratively the country is divided into twenty-seven provinces (fig. 1.1) i.e. Special District Aceh (1), North Sumatra (2), West Sumatra (3), Riau (4), Jambi (5), South Sumatra (6), Bengkulu (7), Lampung (8), Special District Capital Greater Jakarta (9), West Java (10), Central Java (11), Special District Yogyakarta (12), East Java (13), Bali (14), Western Lesser Sundas (15), Eastern Lesser Sundas (16), West Kalimantan (17), Central Kalimantan (18), South Kalimantan (19), East Kalimantan (20), South Celebes (21), Southeast Celebes (22), Central Celebes (23), North Celebes (24), Moluccas (25), Greater Irian (26), and East Timor (27). Each province is appointed a Governor by the Central

Government. The province is subdivided into municipalities (kota-madya), regencies (kabupaten), districts (kacamatan), subdistricts (kemantren), villages (kelurahan) and hamlets (dukuh).

1.0.5 Economy

Since 1949 after the Dutch government of Nederlandsch Oost-Indië transferred the country's sovereignty to the Indonesian government the nation's economy suffered from political instability until 1966. Industrial development was then hamstrung by lack of competent management after the Dutch exodus, insufficient capital investment, lack of raw materials, problems of importing and obtaining capital goods, and the lack of producing facilities for capital goods. Exports were hampered by high cost economy and inconsistent quality control (1.6). After the new order government took over in 1966 notable efforts have been made and progress has been achieved in rectifying the deplorable economic situation. Per capita income has trippled to nearly US$ 600.- in 1985 (1.7).

Agriculture is still Indonesia's major economic activity engaging about 70% of the labour force. Rice is the country's principal subsistence crop followed by maize on the island of Madura, sago in the Moluccas and Irian Jaya. The latter is supplemented with bananas. Under the leadership of President Soeharto the country achieves self-sufficiency in its main food staple of rice production. Other supplementary subsistence foods are: cassava, which is also processed into tapioca flour, soy- and greenbeans, peanuts, sweet potatoes, copra, sugar, eggplant and red pepper (1.8).

Seventy percent of the livestock i.e. buffaloes, cows and horses are on Java and Madura where they are utilised as work animals. For consumption are goats, cows, sheeps, pigs, and chickens. The average farm holding, including house and garden plot is only about 0.6 acre on the island of Java and Madura. Consequently in Central and East Java there is an agricultural proletariat of either hired farm-hands or share croppers. Per capita income was less than US$ 500.- in 1984, with 20% of the total population living below the poverty line (1.9). Crude oil and gas export still accounts for more than 60% of the country's

income. Other exports include rubber, sawn timber, plywood, rattan, latex, veneer, copra, cocoa, coffee, tobacco, tea, pepper, garments, rice bran, palm oil, shrimp, lobster, yelly fish and snail. Mineral's exports comprise of tin, bauxite, nickle, copper, coal, aluminium, cement and iron ore (1.7).

1.0.6 Health

Exact figures on respiratory infections (tuberculosis), skin diseases, gastro-enteritis, malaria and ocular infections are hard to come by, despite the fact that they are the most prevalent communicable diseases. Leprosy, tetanus neonatorum and filariasis are not rare. A child under five years experiences four illnesses per year, consequently the child mortality rate is high under the circumstances of inadequate health care facilities, poor sanitation i.e. inadequate water supply and insanitary excreta disposal, poor housing with overcrowding and an abundance of disease transmitting insects. The United Nations International Children Emergency Fund (UNICEF) success story of GOBI (growth monitoring, oral rehydration, breast-feeding and immunisation) has considerably reduced the mortality rate of children under five years of age (1.9).

The unequal distribution of physicians in the country renders a doctor patient ratio of less than 1:3,000 in some urban areas to more than 1:50,000 in rural regions, but the overall ratio is one in ten thousand (0.1). The national health insurance covers only the government civil servants, the armed forces and their dependents. Private health insurance has yet to be developed.

In 1969 the concept of community health centers or Pusat Kesehatan Masyarakat (puskesmas), providing integrated health services was initiated in all districts of the country and later on in various subdistricts on the island of Java. Each community health center on an average serves around 50,000 people on Java and Madura and far more on the other outlying islands. Its general objective is the provision of integrated health services through the promotion of adequately staffed curative and preventive services. The community health center is responsible for medical care, maternity & child health, family planning, communicable disease control, environmental health, nutrition,

health education, dental health, mental health, public health nursing, school health, simple laboratory services, health statistics, and collection of data for planning and evaluation purposes (1.9). The community health centers are easily accessible in every respect. Aid stations (puskesmas pembantu) are established for remote areas. At present there is at least one community health center in every district of the country and one in every subdistrict on the island of Java. Aid stations in remote areas served by a community health center are being realized step by step.

All community health centers are staffed by medical graduates who have to fulfil government's compulsory service for at least five years on the islands of Java and Bali and three years on the other outlying islands. The majority stays on after completing their term. The minority returns to the cities in the private health sector or embarks on specialisation at state universities. By the Department of Health recognized specialties are: internal medicine, paediatrics, general surgery, and obstetrics and gynaecology. Furthermore nurses, midwives and primary health workers (PHWs) for sanitation, immunisation, infectious disease control and administration belong to the staff of the community health center.

In 1978 the Village Community Health Development Programme (VCHD) or Program Pembangunan Kesehatan Masyarakat Desa (PKMD) was initiated based on the principle of primary health care and Indonesia's traditional village activities of mutual aid or gotong royong where for example the people of one hamlet volunteer to build in rotation a house for one of the community members or where they collectively provide financial aid or labour to build roads or repair bridges. Important decisions are taken by consensus through deliberations (musyawarah) and consultations until everybody agrees and are then followed by community actions.

Each village nominates twenty volunteers (sukarelawan) to be given a course of four months, consisting of two sessions of three hours each a week in: first aid, treatment of minor ailments, personal hygiene, nutrition, sanitation improvement, recognition of communicable disease, and problems related to maternal and child health. They are also taught when to refer

cases to the aid station or community health center, how to communicate with the community and conduct group discussions, and how to motivate the family to take care of their own health. Each village primary health care volunteer (PHCV) is responsible for the health of ten to twenty families. The village community development programme is part of the community programme of the Department of Interior under the technical guidance of the Department of Health and developed through the community health center. There are now more than fifty thousand PHCVs in more than 2,500 villages on the islands of Java and Madura.

Primary health care is almost for free, costing US$ 0.10 (150 Rupiah) per visit including three days supply of medicine. It is extended with a mutual referral system to some district hospitals on the island of Java and to regency hospitals in the rest of the archipelago. These hospitals are staffed by an internist, paediatrician, general surgeon, and obstetrician / gynaecologist each assisted by several general medical doctors. Ambulance transport and inpatient care are free for those who are granted a written statement of destitution by the village head, otherwise minimal charges are levied by these government hospitals.

Another dimension was added to the national health care system when in 1985 the Departments of Health, of Interior and the National Bureau of Family Planning formulated the Integrated Health Service for Family Planning and Health or Posyandu (Pos Pelayanan Terpadu) with as priorities the decrease of the Child Birth Rate (CBR), Total Fertility Rate (TFR) and Infant Mortality Rate (IMR).

1.1.0 Java

Java is the fourth largest island of the Indonesian archipelago. In terms of population density and land use it is also the principle island of Indonesia. Culturally it is the most sophisticated part of the country. It comprises the five provinces of East-, Central- and West Java, Jakarta Raya and Yogyakarta. Jakarta, the capital of the Republic of Indonesia is located on the north western coast and is the center of government and economic activities.

1.1.1 The people

With a land area of 126,501 sq km, Java is the most densely populated island and has 65% of the total population of Indonesia. Although its people share Malayo-Polynesian racial heritage, there are three major ethnic divisions: Javanese 70%, Sundanese 20% and Madurese 10% (1.4).

1.1.2 History

Long before the beginning of recorded history, Java was a center of human activity. Chinese and Indian records of the time of Christ indicate that Java already had a highly developed culture. Java's most important cultural and political period was the Hindu-Buddhist era, from approximately the fourth to the fifteenth century. For the greater part of this period, Java was not the political center of Indonesia, but was included in the Sumatra based empire of Sriwijaya. During this time the devoutly Buddhist and Hindu rulers of Sriwijaya built in Central Java the Buddhist temples Borobudur and Mendut, and the Hindu temples Prambanan, Candi Gedong Songo (Ban-dungan) and the Dieng plateau temples.

By the thirteenth century the Sriwijaya empire had declined and the east Javanese state of Majapahit had become the great power in the archipelago. In the sixteenth century concurrent with the conversion of Indonesia to the Islam and the appearance of the Europeans, Majapahit disintegrated and was replaced by the last great Javanese state of Mataram in Central Java. The history of Mataram was largely the story of its piecemeal absorption by the Dutch United East India Company. The company became the leading European power in the seventeenth century, and by the mid-eighteenth century Mataram had crumbled into the Dutch vasal states of Yogyakarta and Surakarta.

1.2.0 Central Java

Central Java (fig. 1.2) extends from latitudes 6 degrees 22' to 8 degrees 16' South and from longitudes 108 degrees 34' to 111 degrees 40' East. The greatest length of the province is about 350 kilometres and the greatest width is around 205 kilometres. The special territory of Yogyakarta with the status of a province

in its own right, forms an enclave within Central Java, shaped like a triangle, with its base on the south coast and its apex at Mount Merapi. Central Java has a surface area of 34,503 square km. It is larger than the Netherlands but smaller than Switzerland. Besides being in the middle of the island of Java, Central Java is also in a central position to the entire country with the great Indonesian archipelago stretching out to the east, north and west. On the south lies the vast expanse of the Indian Ocean (Indonesian Ocean). The province has a great geographic variety. There are chalk hills in the north-east. The central highlands contain the active volcanoes. The fertile land of the central Java plain, in a bird's-eye view, looks like a sea of rice fields, the villages resembling islands of trees hiding the houses. There are more more chalk hills to the south. A group of small islands called Karimunyawa lies 50 - 70 kilometres out north in the Java sea. The north coast is gradually growing outward with the silt deposited from the rivers that flow from Java into the Java Sea. This created the swamps in the north. There are more swamps in the south-west corner of the province, which is protected from the ocean current by the long island called Nusakambangan. Rawa Pening is a different kind of swamp as it is situated in the middle of the province 42 kilometres to the south of Semarang. It receives the drainage from the surrounding hills. Overall the landscape of Central Java is not only dominated by several active volcanoes, but its soil development and enrichment, agricultural development and population density are very closely related to the location of the volcanoes. The most notorious one is Mount Merapi (Fire Mountain), the country's most active volcano, which is in almost constant eruption. It rises about 2,912 metres above sea level, higher or lower depending upon accumulations at the top. A big eruption occurs about once in five years with outbursts of ash and volcanic bombs, which in itself do not cause much damage. More damage is done by the violent floods of water, huge stones and cold lava turned into mud which sometimes creates extensive destruction of roads, rice fields and villages. Nevertheless it always enriches the soil with volcanic ash and debris. Farmers making use of the rich volcanic soil, cultivate close to the rims of even the most active craters. Because of the heavy annual rainfall, many

extinct volcanoes have become extensive lakes. Of the whole area of Central Java, only 4.6% lies at a height of over 1000 meters; 14.7% has an elevation of between 500 - 1000 meters (the survey was conducted at this altitude); 27.4% ranges from 100 to 500 meters, whilst the remaining 53.3% of the area lies between sea level and 100 meters (1.14). Most rivers run northward, although the longest, the Bengawan (551 km), flows eastward. The major use of the rivers and lakes is for irrigation. The north of Java is flat and low and has many mangrove swamps. The plains of the south consist of marsh and sandhills. Most interior plains are volcanic. Except in the mountainous areas, the climate is difficult to bear. The mean daily temperature varies from 19 degrees to 35,5 degrees Celsius. However, it is the 75 to 90% humidity of the plains and the coastal areas that is so debilitating. January is the wettest month, and August the driest.

1.2.1 The people

In the south plains, where the soil is rich population density runs as high as one thousand people per sq km. Central Java is inhabited by the Javanese. Although the Indonesian Language (Bahasa Indonesia) is the official language, Javanese is used mainly in the communities. Central Java is still the centre of the Javanese culture, history, language and the site of its main historical monuments. For the 80% of the population that lives in rural areas, existence is dominated primarily by the traditional patterns of village activity of gotong royong and musyawarah. The population census of 1980 enumerated the inhabitants of Central Java at 25,367,344 people. The sex ratio of females to males was 1000:951 or 48.6% men and 51.4% women. The sixty-five years and over age-group totalled 3.3% and comprised of 1.6% males and 1.7% females. Less than 1% are seventy-five years or older. English has replaced Dutch as the first foreign language. Among the older generation, Dutch-speaking people can still be found.

1.2.2 Economy

Agriculture is the principle economic activity. Rice is the main staple food. Other agricultural products are: maize, sorghum, pulse, soybean, peanut, cassava, and sweet potato.

Estates produce tea, sugar, coffee, rubber, cocoa, sweet potato, vanilla and tobacco. Industrial activity is mainly home industry or connected with the processing of agricultural products for export. Textiles (garments, carpets, and leather goods) are produced for the home market and export. Batik, an Indonesian hand painted textile, later replaced by iron printing, is concentrated in Central Java. It is a major cottage industry, besides several large scale industrial operations. Labour intensive clove cigarette factories provide employment for tens of thousands of people. Forestry, timber and plywood processing is a growing industrial activity. Although several large scale furniture, ceramic and glass factories are well-established, small handicraft industries and home industries of utensils still dominate the scene. Scattered are one or two food processing industries canning tropical fruits and fish. There are several factories for soft drinks, cement, and tin plate cans. Fish and shrimp culture is developing, the latter mainly for export. Stock raising is still limited to the farmers as a support for agriculture.

1.2.3 Health (1.14)

Notable achievement has been reached in the health sector. Smallpox is now non-existent. Yaws occasionally can still be found in remote areas in a few people as compared to hundreds of thousands formerly. Malaria, tuberculosis and cholera are gradually being brought under control. Dengue fever though endemic is adequately dealt with.

In 1981 - 1982 there were in total 564 Community Health Centers (puskesmas), more than one for every district (kacamatan), 47 general and special public hospitals and 29 private ones, in addition to 3 government and 97 private maternity homes. There were 1,169 general doctors, 153 specialists, 185 dentists, 1,723 midwives, 1,975 nurses, 631 sanitarians and 14,717 other paramedical personnel.

1.3.0 Regency Semarang (fig. 1.2)

1.3.1 The people.

The regency of Semarang has a population of 708,602 people with a population density of 703 people per sq km. It has jurisdiction over 248 villages with 147,976 registered households. The average village harbous 2,857 people and the average household has 4.8 members. In 1981 the number of births was 13,730 and of deceased 4,024. The annual birth rate therefore was nineteen per 1000 and the death rate six per 1000 people as recorded in the Statistics of Central Java 1981. As the annual expected birth and death rates are 4.0 - 4.5% and 1.8 - 2.2% respectively, there is a gross underreporting or non-registration of births and deaths. In 1982 only 3,248 people had migrated to other outlying islands of the archipelago (1.10).

1.3.2 Health

There are only two general hospitals in the regency for secondary health care each served by an internist, paediatrician, general surgeon and obstetrician/gynaecologist assisted by several general medical doctors. The combined capacity of the two hospitals is 169 beds. For primary health care the regency was served by fourty-five aid stations, fourteen community health centers, and twenty-two maternity and child health centers. Influenza topped the annual list of recorded diagnoses with 40,033 cases, followed by 21,513 cases of nasopharyngitis. Gastroenteritis ranked third with 7,528 cases, followed by pneumonia with 3,877 patients. On the fifth place was tuberculosis with 3,339 cases diagnosed. The five top killing diseases were still infectious diseases and they dominated the primary and secondary health care facilities. Underutilisation of health care facilities and underreporting of cases are common.

1.4.0 Subdistrict Bandungan (Kemantren Bandungan)

1.4.1 Geography

Bandungan is a subdistrict fourty-two kilometers south of Semarang, in the district of Ambarawa, which is part of the regency of Semarang (fig. 1.2, 22*). It is a resort area for holidays and weekends, located on the southside of a dead volcano facing the sweet water lake Rawapening and at 750 - 950 meters above sea level. The temperature range is 17 - 25^0 Celsius. The area comprises of 24.5 sq km mountainous land with terraced rice fields. The rainy season lasts 9 months and the dry season 3 months. There were only 10% paved roads at the time of the survey.

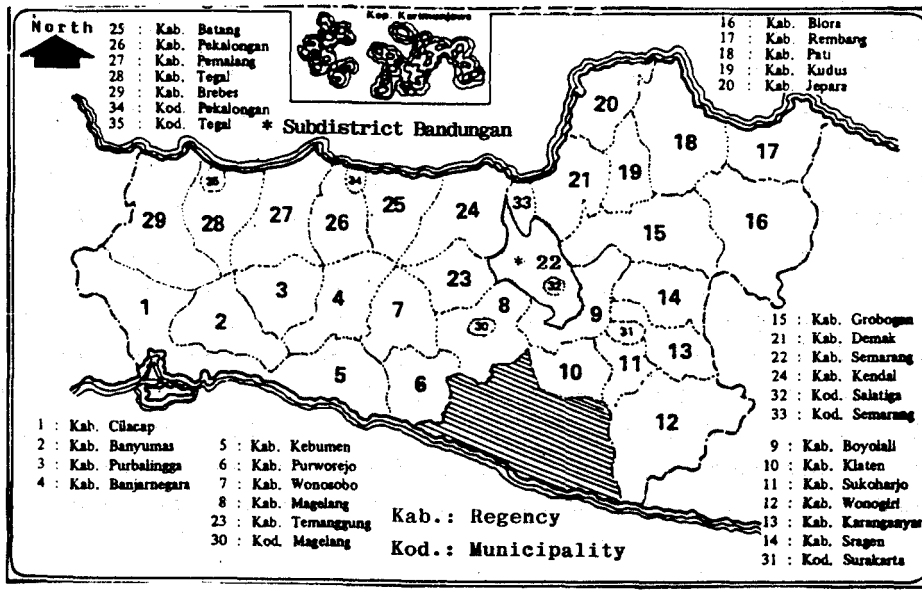

Fig. 1.2 The Subdistrict of Bandungan (*) lies in the District of Ambarawa in the Regency of Semarang (22)

1.4.2 The people

The inhabitants are distributed in five villages with a total population of 38,500, composed of around 5,000 households with an average of eight members per household. The subdistrict has a relatively stable population of rural Javanese. They dwell in well-defined hamlets and their main occupation is rice cultivation and market gardening. Traditionally married couples live with their parents and it is not unusual for two or three generations to live together. The bungalows and villas for weekenders built along the paved roads criss-crossing the villages have little impact on the traditional life-style of the communities. Seventy-five percent of the population is engaged in agriculture and 25% in commerce, transportation, home industry, government service and domestic tourism.

Table 1.1 Sex-specific distribution of heavy, light and non-manual occupation of Bandungan people fifteen years and over (in percentages)

Occupation	Men	Women	Men + Women
Heavy manual	79.8	74.3	76.9
Light manual	10.2	20.1	15.5
Non-manual	10.0	5.6	7.6

Heavy manual: farmer, farm-hand, sharecropper, market gardener, road worker, mason, carpenter, labourer and laundress.
Light manual: cattle trader, vendor, driver, midwife, innkeeper, foreman, tyre patcher, and housewife.
Non-manual : roomboy, teacher, manager, cashier, pensioner, unemployed pupil, student, etc.

The agricultural workforce comprises of 75% female and 25% male farmers and farm-hands. Women are involved in sowing for rice seedlings, planting, maintaining, fertilizing and har-

vesting the rice fields. Men are occupied with preparing the rice field for planting by hoeing and plowing, transport of fertilizer, seed and harvest, and management of the farm i.e. selling, buying and credit application (table 1.1). Three times more women than men are toiling the soil. In between these activities men have more leisure time as the women are additionally occupied with house-keeping which includes cooking, washing and rearing the children. The average lifespan is fourty-five for men and fifty years for women despite the unfair distribution of the workload over the sexes.

Table 1.2 Sex-specific distribution of daily distance walked of Bandungan people fifteen years and over (in percentages)

Distance	Men	Women	Men + Women
0 - 4 km	59.2	48.1	53.2
5 - 9 km	39.6	51.2	45.8
10 + km	1.2	0.7	1.0

As the rice fields, market gardens and village markets are within walking distance, these people do not have to walk far to carry out their daily chores (table 1.2). Still nearly half of this population has to walk 5 km or more daily for their earnings and 40% carry loads of 20 kg or more (table 1.3).

Table 1.3 Sex-specific distribution of weights carried by Bandungan people fifteen years and over (in percentages)

Weight	Men	Women	Men + Women
0 - <1 kg	----	4.1	2.6
1 - 19 kg	48.6	70.3	60.2
20 - 39 kg	45.9	23.6	34.0
40 + kg	5.5	6.1	5.8

Fig. 1.3 The fifth temple is the most completely reconstructed among the group of nine temples (Candi Gedong Songo)

1.4.3 History

The only available historical population data are from 1861, when 256 residents were registered in the subdistrict of Bandungan. The majority or 210 people lived in the village Bandungan. Water was supplied by three wells on the southside of Mount Ungaran (1.11). The only remnants of the early civilisation of the subdistrict Bandungan are the partially restored ruins of the Nine Temples or Candi Gedong Songo (fig. 1.3), which lie in the village Candi, one and a half km from the village of Bandungan. It must have been a center of some importance in the history of the area. No written records are left, but several versions of verbal legends of doubtful reliability exist.

1.4.4 Health (1.13)

An almost for free western style primary health care is provided through one aid station located in the village of Bandungan and one community health center in the village of Duren (fig. 1.4), extending with a mutual referral system to the district (Ambarawa) and regency hospital (Ungaran) providing secondary health care (1.12).

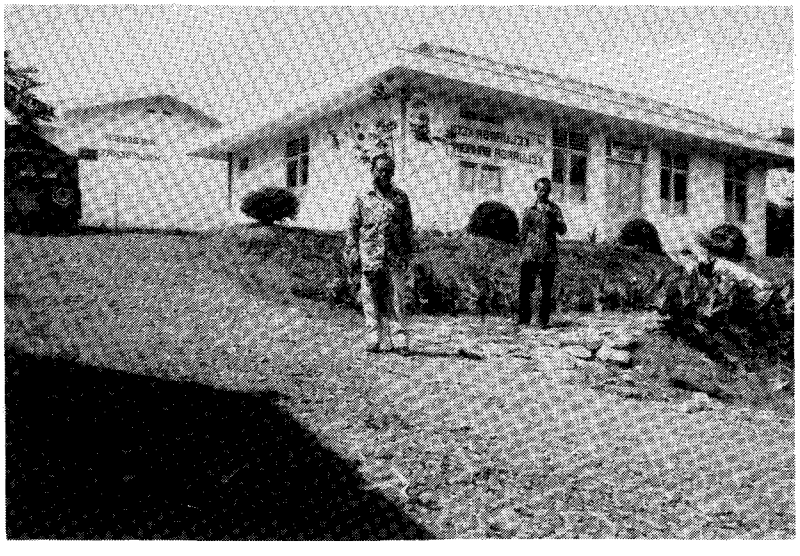

Fig. 1.4 The community health center in the village Duren. From left to right: Mr Ngabdi and Mr Soehatman, the PHWs who carried out the phase two interview survey.

The aid station of the community health center is served by one midwife, one nurse and five PHWs, one for each of the following: drug dispensing, administration, family planning, house calls, and malaria control. The community health center is served by one medical doctor, one part-time dentist, who has to attend three community health centers, two midwives, one nurse, one PHW for each of the following: sanitation, house calls, immunisation, malaria control, assistant midwife, assistant nurse, administration, and three workers for housekeeping. Bandungan being an area for weekenders and recreation one PHW was specially assigned the task of venereal disease control. PHWs had a six month course of primary health care after completing six years of primary school education. Motorcycles were provided for the field workers for house calls, malaria control, and sanitation.

Patients have to pay US$ 0.10 (Rp 150) for examination and three days supply of medicines. Ample supply of medicines are available i.e.: phenylbutazon, methampyron, paracetamol, aspirin, prednison, anxiolytics, antacids, antidiarrhoeals, antispasmodics, diuretics, antihistamines, vitamins and minerals, nutritional fluids, electrolytes, glucose, NaCl, antibiotics, tuberculostatics, antiseptics, desinfectants, antiamoebiatics, antimalarials, antianaemics, digitalis and haemostatics.

In 1982 the community health center and its aid station carried out the following programmes (1.13):

- Maternity and child health.

The community health center and its aid station were visited by 610 pregnant women, the midwives delivered 117 and the registered and/or upgraded traditional village midwives 304 babies, 1,144 lactating women were treated, 1,642 babies less than one year old were seen, 858 one to six years were physically examined. These figures have to be interpreted within the context of the fact that very few pregnant women had their babies delivered by the midwives and the majority of the traditional midwives had not been upgraded nor registered and the babies they delivered were also not recorded. Evidently there was an underutilisation of the midwives and registered traditional midwives. The 1,642 less than one year old babies who were seen

suggest an annual birth rate of fourty-three per one thousand people or 4.3%. The national birth rate was 4.2% in the same year, but has now been claimed to have dropped to 3.5% annually due to an intensive family planning campaign. According to the national figures registered traditional midwives still deliver 72.2% of the newborns, but the number of unregistered traditional midwives is unknown (1.14).

An additional fourty-two traditional midwives were given a course in western style delivery, fifteen play groups were given health education, 140 pregnant women and 331 babies were vaccinated.

- Family planning.

One thousand nine hundred fifty-eight new acceptors for contraceptives were recorded and 4,303 old acceptors were followed up.

- Nutrition.

The UNICEF Growth Monitoring programme consisting of distribution of free milk has induced more mothers to bring their babies and toddlers for examination. Three thousand five hundred eighty-six babies and children less than five years old were weighed. Furthermore high dosed vitamin A was dispensed to 94 children aged one to four years and iron tablets were distributed to 121 pregnant women.

- Environmental health.

Two thousand five hundred people enjoyed piped spring water, 2,500 utilised protected well water, 1,900 had handpumped well water, 450 dug well water and 2,500 were supplied running water by the water supply company. In total only 25.6% of the total population of the subdistrict of Bandungan had the luxury of clean water. Barely 13% of the inhabitants had adequate housing and waste disposal. A miniscule of 7.6% of the houses fulfilled sanitary requirements. Thirty and a half percent of the people had the gratification of sanitary excreta disposal.

- Prevention and eradication of communicable diseases.

Only five new cases of tuberculosis were treated, which

indicated a grave underutilisation of the tuberculosis control facilities and underdiagnosis of the disease. Unless patients coughed up blood they were unlikely to visit the community health center or its aid station. This may account for the low annual incidence of tuberculosis reported.

- Health education.

One hundred and fourty-two times community education on community hygiene was launched.

- School health.

Two hundred twenty first graders from twenty-eight primary schools, fourty-six first graders from two junior high schools and nineteen first graders from one senior high school were examined, while 848 first and 648 six graders from primary schools were vaccinated for diphtheria and tetanus.

- Public health.

One hundred and twenty households were visited and 129 households followed up for unreported reasons. Eighty-seven high risk (contagious disease) cases were identified but diagnoses were not recorded.

- Dental health.

Ninety-three pupils were treated at the community health center and 1,378 pupils were treated by school visits. Twenty-eight schools were visited for dental care.

- Mental health.

Two hundred ninety-seven neurotic cases were diagnosed without identification of the type of neurosis.

- Medical care.

The annual number of patients seen at the community health center and its aid station was 10,330 of which 8,565 were new or old patients with a new diagnosis and 1,765 follow up cases with an established diagnosis. The disease categories predominantly diagnosed were infectious diseases i.e. influenza, nasopharyngitis, gastroOenteritis, skin and ocular infections. Rheumatism

was seen in 5% of these patients, which was around half of that seen in the primary health care of developed countries (1.15).

- Simple laboratory procedures.

One thousand six hundred and thirty-five blood samples were taken for haemoglobin determination.

Although most of these figures might look impressive, it should be realized that they generally underrepresent the real problems of the area. Problems of the locomotor system are seen in 5% by the commmunity health center and although only a minority of the population belongs to the aging segment, even the utilization of the primary health care services by the younger age groups is about one third of that observed in developed countries.

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CHAPTER II

THE WHO-ILAR COPCORD

(The World Health Organization - International League Against Rheumatism Community Oriented Programme for the Control Of Rheumatic Diseases)

2.1.0 Historical background.

During the seventies the International League Against Rheumatism (ILAR) urged the World Health Organization (WHO) to launch a major programme for control of rheumatic diseases. Up to then WHO had been active in rheumatic fever (since 1950) and Ross River Virus Arthritis control under the supervision of the Division of Communicable Diseases.

Since in 1977 on the request of ILAR World Rheumatism Year was declared by WHO, a series of meetings took place aimed at initiating a rheumatic disease control programme under the auspices of WHO and ILAR. As at the end of the seventies the WHO Division of Non-communicable Diseases was involved in initiating a programme for the control of cardiovascular diseases Drs Allander (Sweden) and Valkenburg (the Netherlands) came to an agreement to take the initiative for a similar programme for the control of rheumatic diseases. After discussions with Dr. I. Glasunov, WHO Division of Non-communicable Diseases, the first draft on a community oriented programme for control of rheumatic diseases was prepared by Dr. H.A. Valkenburg. This draft proposal which described potential survey models applicable in rural and urban settings in both developing and developed countries was discussed at the first WHO-ILAR meeting called by WHO in January, 1981 in Geneva, Switzerland (2.1). Among the attenders to this meeting were the three members of the ILAR Standing Committee on Epidemiology, Drs E. Allander, H. Boffi-Bogero and R.D. Wigley, representing EULAR (European League Against Rheumatism), PANLAR (Pan-American League Against Rheumatism) and SEAPAL (South East Asia and Pacific Area League Against Rheumatism) respectively. During the meeting it was made clear that WHO was principally interested in a world-wide programmatic approach with emphasis on the majority of the world population living in the rural areas of developing countries while their

main concern was with the commonest rheumatic diseases such as osteo-arthritis and extra-articular rheumatism believed to be the major cause for most of the suffering and pain (2.2). In the initiation of the COPCORD programme one ILAR president i.e. Dr. Ray Robinson played an important role, while on behalf of WHO support was given by Drs V. Grabauskas and M. Mitrofanov, both of the WHO Division of Non-communicable Diseases. The ILAR Standing Committee on Epidemiology under the chairmanship of Dr. E. Allander showed a continued interest and participated in most of the discussions on this subject. It was by Dr. K.D. Muirden's endeavour, at the time president of SEAPAL, that things got coordinated and a COPCORD pilot survey was initiated in the Philippines and later on extended to Indonesia (2.3).

Before considering the actual control of rheumatic diseases, information was needed on prevalence rates in developing countries. WHO representatives suggested that the risk factor approach used in cardiovascular diseases could equally be applied to e.g. osteo-arthritis in seeking new information on patho-genetic determinants (2.4 and 2.5).

2.2.0 The COPCORD Programme.

The COPCORD programme comprises of three stages. The first stage is a population survey to provide data on the prevalence of rheumatic diseases, perceived need for intervention and the magnitude of disability, followed by a second stage of education of (para)medical personnel in the existing primary health care system on rheumatic disease management and disability prevention. Stage three intends to improve health care in the existing primary health care system and is directed towards early diagnosis, treatment, selfhelp and assistance in coping with musculoskeletal disorders by the health care personnel trained in stage two (0.2).

2.3.0 Aim of COPCORD

The primary objective of COPCORD is the community control of rheumatic diseases by both prevention and treatment of pain and disability through its programme of three stages. Before this goal can be achieved, it is necessary to identify the magnitude of the problem as a whole and the individual in the community who needs help and support, but does not receive it and those who get inadequate treatment. For that reason the programme has to start with an epidemiological survey. However, due to lack of manpower in epidemiological research and financial constraints in most developing countries the survey should be designed in a cheap and efficient way, albeit at the expense of some losses in validity and ascertainment. For that reason the survey model was designed in three phases, based on the principle that from each phase the relevant people (e.g. those who were expected to need help) would be sieved and referred to the next phase, finally to be left with those individuals who would be in the greatest need for treatment or support and not receiving it or receiving inadequate care.

Phase one therefore was designed as an interview survey to be carried out by primary health care volunteers applying a simple questionnaire on pain, disability, coping and perceived need of treatment. The minimum number of adult inhabitants of a designated community to be approached was set at 1,500. In phase two the respondents with joint and/or neck and/or back pain from phase one were to be interviewed by a trained nurse with a more detailed questionnaire which would allow classification of the respondents by distribution of symptoms. In phase three the phase two cases with more definite rheumatic disease or those with perceived need for treatment as identified by the nurse were to be examined by medical doctors familiar with rheumatic disorders but without applying laboratory procedures, such as serology and radiology, which were considered to be too expensive.

2.4.0 The Philippine COPCORD

With seed money from WHO and ILAR a phase one pilot study was initiated in the Philippines in 1981 under the direct supervision of Dr. L. Manahan after on site inspection of the survey area by Dr. H.A. Valkenburg. It was executed by primary health care volunteers (PHCV) in San Antonio village in the Bay Lagoona area in the Philippines. Phase two was carried out by a midwife of the public health center. Phase three was completed by Drs L. Manahan, K.D. Muirden and R.D. Wigley, respectively Local Resource Person, Coordinator and Member of the WHO-ILAR COPCORD Team.

2.5.0 The Indonesian COPCORD (2.6)

Having heard in 1980 about the COPCORD survey mentioned above the author was approached early 1982 by Drs K.D. Muirden and R.D. Wigley on the possibility of executing a rural COPCORD population survey in Indonesia. This matter was further discussed during the Biennial Australian and New Zealand Rheumatism Association Meeting in Rotorua, New Zealand, in October, 1982. Drs Valkenburg, Muirden, Wigley and the author attended that decisive conference from which the Indonesian COPCORD study emerged. In the meantime, from April, 1982, onwards preparations were already made for an eventual realisation of this study such as fund raising, training of the PHWs, a pilot study of the phase two questionnaire and in particular familiarisation of the author with the community to be studied.

2.5.1. Motivation

Despite the relevance of musculoskeletal disorders both to the society and to the many individuals affected, in the developing countries attention generally tends to focus on disorders associated with a high mortality rate such as infectious, cardiovascular and malignant diseases, rather than on diseases that primarily affect the quality of life and economic productivity. Much what is known about disease has been limited to findings from reports of series of hospitalized cases. Such

series generally are not representative for disease as seen in the general population as the vast majority of musculoskeletal disorders are not admitted to the hospital and in many cases may not even come to medical attention. Thus community surveys are necessary to learn about the extent of the rheumatic conditions. Rheumatic diseases are presently a non-priority item of the government in almost all developing countries. So far most efforts have been rightly directed at acute mortal diseases, whereas chronic crippling diseases have been relatively neglected. It may be envisaged that in most developing countries the improving life expectancy will increase the burden of chronic conditions such as rheumatic diseases with all its social and economic consequences. Incidentally chronic musculoskeletal disorders may already have hindered the development of third world countries. The COPCORD design may then provide a means to obtain relevant population data, which can be used to study changes in the impact on society of musculoskeletal disorders over the coming decades.

2.5.2 Design of the study

Phase one was left out of the Indonesian study for reasons of ignorance, pragmatic considerations, financial constraints and the fact that the author was left to chose between the phase one and the more elaborate phase two questionnaires without having any financial prospect of the execution of a consecutive two phase's study. When finally phase three was completed twenty months after phase two, a phase four epidemiological case-control study was added including serology and radiology. The latter was executed by rheumatologists under guidance of an epidemiologist and provided diagnostic categories. From this case-control design the observed prevalence rates of the rheumatic disease categories could be recalculated to the original population of phase two.

In the original design phase one was supposed to be carried out by primary health care volunteers or laymen not holding a job in the primary health care system. Phase two in Bandungan was carried out by two PHWs who did hold a regular job at the community health center and its aid station. They were educated for six months in primary health care after completing six years of primary schooling. Both had been in service before and after the

second world war for the eradication of plague, yaws, smallpox, malaria, and the control of tuberculosis, diphtheria, tetanus, pertussis, typhoid fever and cholera. They had served the designated COPCORD survey area for more than thirty years and knew almost every adult of the villages Bandungan and Duren. Relying upon the experience of the community health center nurse and midwife, they were able to engage in private practice after office hours dispensing drugs and intramuscular injections such as vitamins, analgesics, antipyretics, spasmolytics, oxytetracycline and penicillin!

In phase three the controls and cases were examined by two rheumatologists, incidentally assisted by a neurologist, and two internists with some interest for rheumatic diseases.

Phase four was executed by an epidemiologist and two rheumatologists. Blood samples were taken and processed by one midwife and one PHW. An experienced mobile X-ray team which used to tour the province of Central Java for chest radiographs was hired for taking X-rays.

By cluster sampling of five villages in the subdistrict of Bandungan, the total population of two villages fifteen years and over was selected for the phase two interview survey. Respondents with current peripheral joint and/or neck and/or back pain who still had complaints at the end of the phase two study and an age- and sex-matched control group of half the size were examined in phases three and four. Respondents who had lost their complaints before the end of phase two and those suffering from thiamine deficiency symptoms but included by the PHWs as suffering from musculoskeletal pain were excluded.

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CHAPTER III
POPULATION AND METHODS

3.1 Population

The Subdistrict of Bandungan, District Ambarawa, Regency Semarang, in the Province of Central Java is composed of five villages. The villages of Bandungan and Duren were selected randomly for the phase two COPCORD population survey. For reasons of response and practical execution, all the inhabitants fifteen years and older of the six hamlets of Bandungan and ten hamlets of Duren were included in the survey. By mistake the PHWs also incorporated the population fifteen years and over of two hamlets in the adjoining village of Kenteng in the survey (fig. 3.1). The smallest hamlet had a population of 24 and the largest of 741 adult people.

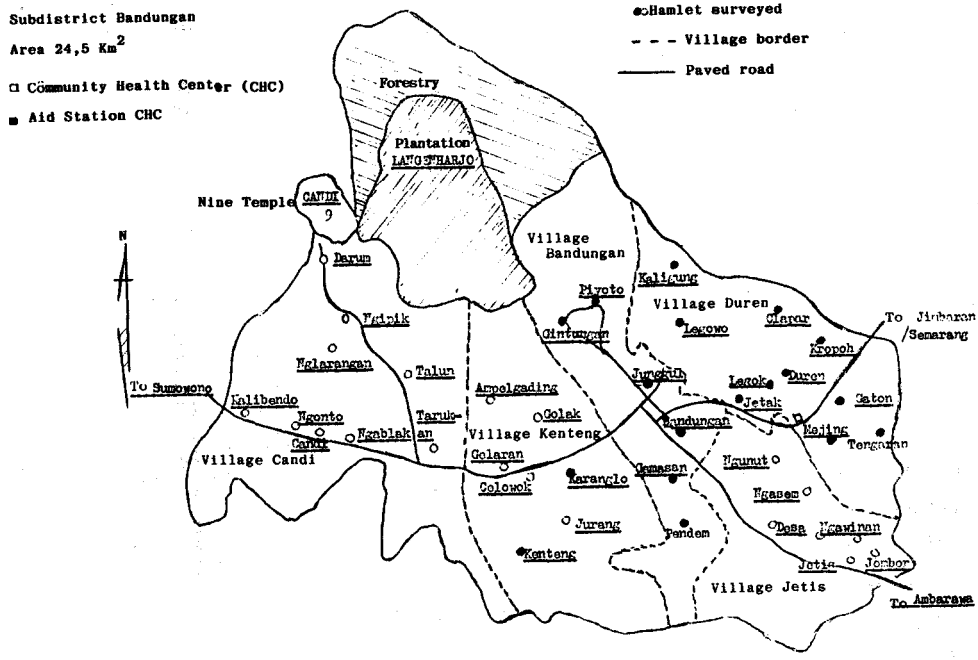

Fig. 3.1 The Subdistrict of Bandungan

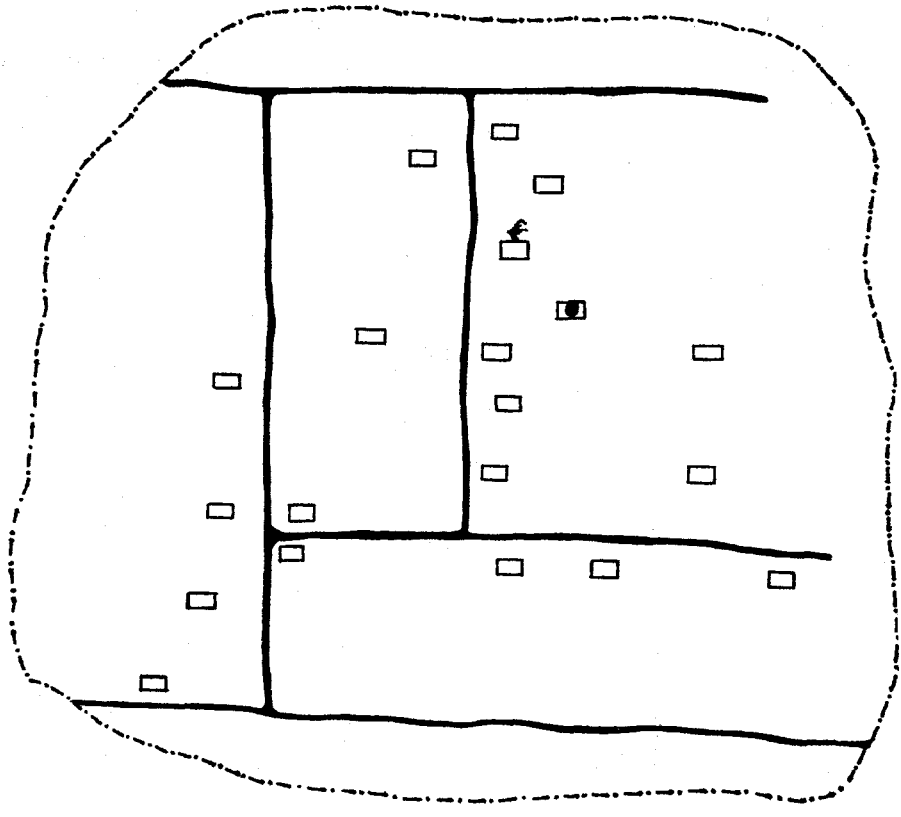

Fig. 3.2 The small-sized hamlet of Kropoh

Except for living at an altitude of 750 - 950 meters above sea level, this population sample resembles eighty procent of the inhabitants of Java and Madura in average lifespan, sex distribution, income, race, religion, culture, and social class. Java and Madura have a total population of around one hundred million.

3.2 Method of registration

Phase two.

Every year the household registration is updated with regard to birth, death, marriage, occupation and migration by the head of the hamlet. At a higher administrative level the village office maintains a corresponding continuous population register. After cross-checking the hamlet household registration (table 3.1) with the village register, the hamlet household registration was elected to be used for the COPCORD population survey for reasons that the hamlet head knew everybody by sight. Table 3.1 does not list those below fourteen years as these figures may have been tailored to give the impression of a successful execution of the family planning programme in the area and underrating of children by the hamlet head was quite possible.

Table 3.1 The hamlet household registration of the target area

Village	Hamlet	Age more than 15 years Male	Female	Total
Kenteng	1. Karanglo	361	380	741
	2. Kenteng	159	189	348
Bandungan	3. Pendem	151	167	318
	4. Gamasan	109	135	244
	5. Bandungan	343	383	726
	6. Junggul	152	173	325
	7. Gintungan	173	199	372
	8. Pijoto	127	150	277
Duren	9. Legok	52	60	112
	10. Kaligung	11	13	24
	11. Legowo	102	116	218
	12. Jetak	98	111	209
	13. Duren	112	122	234
	14. Ciapar	33	42	75
	15. Kropoh	45	56	101
	16. Gaton	35	40	75
	17. Mejing	85	90	175
	18. Tengaran	54	65	119
Total		2202	2491	4693

One week before the interview took place, each of the eighteen hamlet registers were checked by the PHWs on whether the people who lived there for at least five years were registered as permanent residents. Having served the area for more than thirty years the PHWs knew almost every household head. All hamlet heads were very cooperative which made the registration of respondents easy.

After it was decided that the phase two study was to be followed by a phase three, serial numbers were given to the completed phase two questionnaires of those respondents who had joint and/or neck and/or back pain within two weeks of the interview and to an age- and sex-matched sample of respondents who never had musculoskeletal complaints. The phase two questionnaire required listing of first and surname, which was from the very beginning rather confusing for the PHWs because the common Javanese people do not have a surname. Except for the nobilities where family names passed on to the successive generations, surnames are only recently introduced in intellectual circles. Whatever was listed as surname in the completed phase two questionnaires was obviously whatever the PHWs thought was appropriate to serve as a surname e.g. the name of the head of the family or household which may not have been the same as the name of the other members of the household.

Phase three.

The 841 phase two cases who still had musculoskeletal complaints and 421 age- and sex-matched control respondents who never had rheumatic pain were registered for the phase three examination based on first and surname, age, sex, and address recorded in the completed phase two questionnaires. They were requested to appear at the aid station of the community health center at a designated time and day, where they were once more verbally checked by the PHWs for first and surname, age, sex, and address, before the personal data and serial number were transferred to the phase three questionnaires and examination sheets. Unfortunately the phase three proforma only listed name, age, and serial number without splitting the name into first and surname, which again confused the PHWs.

In the turmoil of reregistration for phase three, the PHWs

were not consistent in transferring names from the phase two to the phase three questionnaires. In a considerable number of instances either the first or the surname from phase two was listed in phase three as the person's name. The problem became even more complicated as one person could have several names or aliases. To turn one's misfortune, ill health or bad luck, the mystical healer or soothsayer or fortune teller may often advise to change one's name. The time interval between phases two and three was twenty months, and without doubt quite a few had changed their names following the recommendations of the soothsayers which was proved by identity check when they appeared for the phase three examination.

Similar misunderstanding arose with regards to the people's age. But for the intellectuals the rural people did not know their exact age. They remembered what their parents told them such as that they were born around the time of the eruption of a vulcano or the land was flooded or during the Japanese occupation or when the Dutch colonial government was still ruling the country. The PHWs then made an estimate of the respondent's age. Hardly anybody knew his or her actual birth date. When asked they gave their age as it came to mind. No wonder that on different occasions different ages were mentioned, resulting in dissimilar ages recorded for the same respondents in the phases two and three. For practical reasons it would have been better when for phase three two years would have been added to the age indicated in phase two corresponding to the time-lag between the execution of the respective study phases.

In the end the only reliable way to ascertain whether the transferred serial numbers were correct, was verbal checking of name, age, sex and address by the PHWs, who knew most of the respondents by sight. Subsequently the PHWs were checked by the author and colleagues whether they had not mixed up the identity of the respondents. The doctors always rechecked the respondent's name, age, sex and address before commencing with the phase three questionnaires and examination sheets. This changing of family and first names, and uncertainty about ages means that one cannot use a computer algorithm to check on correct entries by means of name and/or age.

Phase four.

The same procedure was followed as in phase three. The original list containing the 841 cases and 421 age- and sex-matched respondents without complaints used in phase three was given to the heads of the hamlet and the respondents were registered by first and family name, age, sex, and address as recorded in the completed phase two questionnaires one week before the phase four examination started. When the respondents appeared, they were checked again by the seasoned PHWs on these items before the serial numbers were transferred to the phase four examination sheets where the only identification was the serial number. The author and his colleagues rechecked the first and surname, age, sex and address with the serial number before starting the examination as the completed phase two questionnaires were always attached to the phase four examination sheets.

3.3 The examination in the various phases

Phase two.

After the pilot study of the translated questionnaire proved to produce accurate and reliable results, the two experienced PHWs started on November 1, 1982, with the house to house visits in order to interview the population 15 years and older in the designated hamlets. It was considered opportunistic to visit the homes after 5 p.m. when all the farmers and farm-hands had returned for the evening Moslem prayers and dinner.

When the respondents gave an affirmative answer to the question whether they "ever" had joint (Q1) and/or neck (Q18) and/or back (Q23) pain, the primary health care workers marked the painful sites in the mannekin with an cross (X) for pain, a circle (O) for swelling and brackets [] for redness or warmth. Superimposed signs were used for combinations of symptoms and signs. For reasons that there was no connotation or a word for "ever" in the local dialect, "ever" was translated into "past". Thus past peripheral joint pain was recorded in the mannekin. Due to a misplaced instruction in the phase two questionnaire current neck pain and current pain in the middle of the back had also to be marked in the mannekin by the PHW. For questions on movements

of the head (Q20-22) and back (Q28-30) the subjects were asked to demonstrate the range of neck and back movements (see appendix 2).

Phase two was executed during the wet season when every day after 2 p.m. torrential rains poured down, which indeed was a blessing in disguise as nobody would venture to go out and therefore was found at home. A high response rate was achieved and few second and third visits had to be arranged. Only occasionally one or two fourth or fifth visits had to be carried out to contact those who could not keep an appointment at the stipulated time and place. By checking the personal data of the completed questionnaires with the name list the hamlet heads had provided it was possible to know who had been missed. One day before the actual interview took place the hamlet heads were asked to urge the people concerned to at stay home the next afternoon for the primary health care workers to visit them. Two people belonging to a singular religious sect refused to be involved in the survey.

As the people still used the local dialect of Javanese as their first language and the Indonesian language was reserved for official occasions only the questions in the questionnaire formulated in the Indonesian language were on the spot translated into the local dialect by the interviewers.

After every weekend checking on the spot was carried out by the author and sometimes assisted by other colleagues. A random sample of initially 20% and later 10% of the completed phase two questionnaires was selected for this check and inaccuracies and mistakes found were later discussed with the PHWs. Most errors were clerical in nature due to fatigue or haste. In one hamlet the complaint rate of current pain was nearly 70%, but checking on the spot proved most of them to suffer from hyperaesthesia and paraesthesia due to vitamin B1 deficiency as verified by a neurologist. They were excluded from those suffering of peripheral joint pain. The PHWs were urged not to hurry and work long hours. During January, the wettest month of the year, the weekly return of completed questionnaires dropped down to 50% in comparison with December 1982, but nevertheless the population survey was completed on January 19, 1983.

Phase three.

After repeating the questions and reviewing and correcting the answers given in phase two, additional questions were asked (appendix 3 no. 46-58) on religion, race, duration of occupation, average weight carried and distance walked daily, light or heavy manual labour, offspring, literacy and medicines taken for musculoskeletal pain.

Height and weight were measured and using a caliper width of the knee across was measured one centimeter above the knee joint.

Flexor and extensor tendons of the wrist, and flexor tendons of the fingers were examined for pain or tenderness, snapping, swelling, limitation of movement and nodules. All the peripheral joints were checked for pain at rest, pain on motion or tenderness, swelling of soft tissue or swelling due to fluid or bony enlargement, joint or synovial crepitus, and restriction of movement. Heberden's nodes were graded from 1 - 4. Grade one stood for the presence of a Heberden's node at one DIP joint, grade two for the presence in more than one DIP joint, grade three for the presence in more than one DIP joint with some discomfort and/or disability and grade four for deformity of the DIP joint with angulation of the distal phalanx in two or more joints.

Particularly tophi and rheumatoid nodules were looked for. Neck, dorsal and lumbar symmetrical and asymmetrical restriction of movement, deformity, nerve root pain, pain on movement and tenderness were recorded when present.

One day before the physical examination the hamlet heads were supplied a list of names of respondents who had complaints at the time of the phase two interview and the age- and sex-matched control group. The hamlet heads were kindly requested to urge their subjects to attend the examination at the aid station of the community health center. When the respondents appeared, they were first checked by the primary health care workers on the personal data in the completed phase two questionnaires, before they were sent on to the doctors. The phase three questionnaires and examination sheets were attached to the phase two questionnaires in case a second identity check was needed (appendix 3).

A car was rented to pick up those respondents who did not

show up. Most of them were found at the market selling their daily crop or were working at the rice field or market garden. The thought never occurred to the author that particularly the controls and specially the farm-hands who did not have any complaints and had no reason to come for free medicines would lose one day's earning by participating in the survey.

Phase four.

There was a time-lag of thirteen months between phases three and four. As in phase three, one day before the examination, the hamlet heads were given a list of names derived from the personal data of the phase two completed questionnaires. The hamlet heads were asked again to urge the subjects on their list to attend the examination at the survey center located in a bungalow of a local motel. The first week enough respondents turned up on their own account, but the second week two cars had to be rented to pick up the people at a meeting place in their hamlets or by house to house visiting. Again they were checked for their identity at the veranda of the bungalow by the two primary health care workers (Fig. 3.3), and subsequently waited in the living room for their turn to be X-rayed (Fig. 3.4).

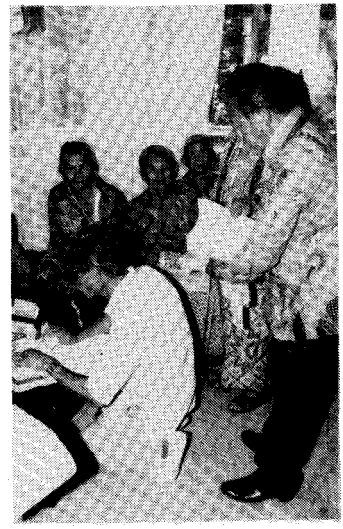

Fig. 3.3 Identity check of the respondents by the PHWs before the X-ray session.

Fig. 3.4 The phase four respondents waiting for their turn to be X-rayed

After their feet and hands were radiographed and where necessary other films were made, and blood samples were taken by one midwife and one primary health care worker, a second identity check was carried out by the author. Very few mistaken identities were discovered. After the second identity check the respondents were examined by Drs Muirden, Valkenburg, the author and at times by Drs Sunarto and Wirawan.

Physical examination of the joints was performed in a standardized way. Limitation of movement was scored on a five points scale. Grade 1 was just perceivable limitation, grade 2 limitation up to 20%, grade 3 up to 80% and grade 4 more than 80% (appendix 4).

The neck was examined with the respondents in sitting position and the examiner standing behind him. The back was examined in prone, sitting and standing position depending upon the movements to be examined. When necessary knee and achilles tendon reflexes were tested. Straight leg raising was tested in sitting position.

Table 3.2

F L O W S H E E T O F T H E S U R V E Y

P H A S E T W O

Hamlet household registration

House to house visit by the PHWs

10 - 20% random sample checking by the author

2 0 m o n t h s i n t e r v a l

P H A S E T H R E E

Registration of the 841 cases and 421 age- and sex-matched controls from phase two.

Identity check by the PHWs and the author.

Review of phase two answers by the author and colleagues.

Physical examination by the author and colleagues.

1 3 m o n t h s i n t e r v a l

P H A S E F O U R

Registration of the 841 cases and 421 age- and sex-matched controls from phase two.

Identity check by the PHWs and colleagues.

X-rays of feet and hands.

Blood samples taken.

Physical examination by the author and colleagues.

3.4.0 Questionnaires

3.4.1 The phase one questionnaire

The original phase one questionnaire used in the Philippines consisted of a number of questions for each household (appendix 1) to seek information on age, sex and occupation, pain at the time of the interview, duration of pain, type of treatment and by whom, whether it was effective, and pain sites marked on a mannekin with front and back views for the hand, elbow, shoulder, cervical spine, thoracic spine, lumbar spine, hip joint, knee, ankle and foot. Disability was featured with diagrams and

questions on whether the subject was unable to hold, stand, walk or carry objects. The appearance of the abnormal part of the body was to be recorded, for example whether it was swollen or bent. Due to interpretative problems with the phase one questionnaire, it was later modified and applied in a different version in the Australian survey (appendix 5).

The phase one study was to be executed by primary health care volunteers (PHCV). The Indonesian COPCORD population survey omitted phase one for reasons mentioned under 2.5.2.

3.4.2 The phase two questionnaire.

The original English questionnaire (appendix 2) used in the Philippines was translated into the Indonesian language. Translation back into English revealed that the word "trouble" in the question "Have you ever had trouble in the joints of your upper and lower limbs?" (Q1) and "Who have you seen for help with your joint, neck and back trouble?" (Q32) was automatically changed into "pain" as the word "trouble" in the Indonesian language would have confused both the PHWs and the respondents. Besides the word "ever" can only be translated in the local dialect by a word which means "past" or "in the past", but does not include the present state. Ever joint pain in English means pain in the past and now. In the local speach it means past joint pain only. Furthermore four more questions (Q36-39) were added after question no. 35. The question whether the injury was due to work (Q6) which was related to "If the injury recovered did the joint pain relapse again?" (Q9) should have had specified the time interval between the initial event and the second attack of pain. Several respondents related present joint pain to an accident 30 - 40 years ago and it was difficult to get the proper facts out after such a long time. Answers to the question "Did the big toe swell with the pain?" (Q11) may have included hallux valgus and bunion, which may have been construed as swelling by both the PHWs and the respondents. The question "Was the big toe red with the pain?" (Q12) may have been missed in dark skinned people. In acute gouty arthritis, the skin overlying the affected joint does not turn red, but only darkens in colour and becomes shiny. The question on the presence of morning stiffness certainly created confusion for the PHWs of how to phrase it in the

local dialect and for the respondents to grasp what was meant by it. "Do your hands, feet and limbs move easily when you wake up?" (Q14a) and "Do you usually wake up with stiffness/aching in your joints and muscles?" (Q14b) were not clarified by the following two questions: "How long does it take for your limbs to loosen up in the morning?" in hours and minutes (Q15a) and "Does this stiffness or aching last more than fifteen minutes?" (Q15b). Both questions were inappropriate as almost none of the people had a clock or watch. Time was estimated by looking at the position of the sun. The final question on morning stiffness "Does this stiffness/aching last till you have passed water or have dressed or have had breakfast?" (Q15c) was still not sensitive enough to pick up appreciable morning stiffness for several reasons. Passing water takes less than one minute for people wearing a sarong (a colourful patterned piece of cloth the ends of which have been sewn together) and with toilet facilities anywhere nearby at a few meters distance. People do not wear more than one layer of cloth and often the sarong and shirt they wore in bed were also used the next day. For that reason not much time was needed for dressing. Virtually none of the rural people had breakfast. Therefore the final question (Q15c) was inappropriate too. Furthermore mixing two subjects in one question (stiffness with aching of joints) made these questions dualistic and confusing. Consequently the concept of morning stiffness was misunderstood and its prevalence was underrecorded. It would have been appropriate to investigate what words or sentences the rural illiterate and semiliterate people used in their local dialect for "morning stiffness" before translating the English directly into the local dialect. The question "Is there a grating sound when the joints move?" (Q16) could have yielded a greater response when more attention had been paid to *crepitus* of the joints. Reduced hearing in the older age-groups where most of the joint crackling occurred and accustomed to hear for years or decades joint crepitus everytime the joint moved probably caused the people to ignore it as something inherent to their body system. When asked they answered no, but when crepitus was demonstrated by letting them move their shoulders or knees they acknowledged the crackling of the joint. "Have you ever had pain in the neck?" (Q18) was translated for past pain in the neck. The

question "Have you ever had pain in the back?" (Q23) was translated by the PHWs as past pain in the **upper** back. In the Indonesian and Javanese language the back is divided into an upper (punggung=geger), a lower (pinggang=bojok) and a sacral region (pantat=bokong). Question twenty-four "Have you had pain in the back in the last two weeks?" was translated again into upper back pain in the last two weeks. Upper and lower back pain in the last two weeks were covered by Q23 and Q24 and sacral back pain was not asked for, which was anyhow a tabood area. This may have lowered the current overall back pain rate. Unfortunately the question "Do you need help for your joint, neck and back pain?" (Q46) was translated into whether they needed treatment for their joint and back pain. Whether they needed help in terms of support or self-care was not asked for. Disability may have been underreported as the questions on disability covered only the most important activities of daily living such as stopping work, being unable to walk, lift, dress and carry (Q40-44) and did not cover all the impairments of self-care i.e. getting in and out of bed, teethbrushing, taking a shower or bath, hairdressing, the use of simple toilet facilities, drinking and eating, household activities, and transport. These latter items may have increased the total disability rate.

3.4.3 The phase three questionnaire.

Particularly in the elderly people revision of the questions asked in the phase two survey was not easy as fading memory confounded the second interview. Nevertheless not many corrections had to be made and only a minority of the original respondents without complaints had turned into complainers in the mean time. The question on loads carried in work, and distances walked during work and daily sports (Q50, Q51) were phrased in such a way that the answers were more guesses than anything else and analysis was futile (appendix 3). The classification of manual work into heavy, light or repetitive (Q52, Q53) was very difficult. Even the carriers of heavy loads did not consider their work as heavy. For decades this was something they had to do to earn a living and it was accepted as daily routine. The farmhands worked from dawn until sunset, but still considered their work routine and light. The women who managed the household

and helped to till the vegetable garden or rice field neither considered their job to be heavy.

As repetitiveness was undefined it was impossible to categorize manual work as such. Scrubbing the floor, washing clothes, hoeing and painting, and carpenter work could under the circumstances be considered to be repetitive.

Almost none of the respondents who took medicines, herbs or pills knew what they were taking, except the most popular ones such as Rheumacyl. It was rather frustrating to record this in the phase three questionnaire.

Item no 62 required to write down the clinical diagnosis before the clinical examination. This was mostly deleted as the clinical diagnosis could only be established by clinical judgement based on symptoms and signs. The completed phase two questionnaire did not list enough symptoms and signs for establishing the clinical diagnosis of common rheumatic diseases.

3.4.4 The phase four questionnaire

The interval between the phases three and four of the COPCORD population study was thirteen months. The phase four examination sheets were more elaborate than the phase three ones as they included serology and X-ray procedures. Unfortunately in the examination of the knee joint swelling whether soft (tissue or fluid) or bony was omitted (appendix 4). However in phase three knee swelling was recorded and this finding was transferred to the phase four data base.

Pain was recorded as present or absent (1 or 0). Restriction of joint movements was graded from 0 - 4 where grade one meant just perceived restriction of joint movements, grade two limitation up to 20%, grade three from 20 - 80% and grade four more than 80% restriction. Disease categories were either recorded as present or absent or graded from 0 - 4 according to the "Manchester grading for clinical disease" (3.1).

Additional questions on workdays lost, working capacity and well-being affected by musculoskeletal disorders were asked. Working days lost were rather difficult to record in the older age-groups, due to declining recollection, seasonal employment, disguised unemployment and seasonal peaking of work activities during the harvest and planting season. In between the harvest

and planting seasons there were no full workdays except for part-time maintenance of the rice fields. Rating of loss of work capacity or well-being could only be related to current complaints. When the condition occurred ten, twenty or thirty years ago, it was impossible for subjects to remember whether their working ability was better, worse or the same after a musculoskeletal spell.

3.4.5 Pilot study of the phase two questionnaire (table 3.3).

After two sessions of instruction of two hours each, the PHWs were advised to translate during the interviews the questions phrased in the Indonesian language on the spot into the local dialect as the majority of the older people only spoke Javanese. In answer to the question who the respondent had seen for his/her joint, neck, or back pain, not only the doctor, nurse, PHW and traditional healer were mentioned, but also the acupuncturist, the masseur, and self-medication with local and imported herbs or drugs. These items were added to the original questionnaire.

After the first trial run it became apparent that the question on current back pain (Q24) was not easy to translate. The Javanese dialect distinguishes three parts of the back. Upper back is punggung, lower back is lambung which in the Indonesian language means stomach, and the sacral region is bokong. As the original questions were rather equivocal the following construct was used. "Have you had pain in the back in the last two weeks" (Q24) indicates upper back pain **now**. "Have you ever have pain in the back" (Q23) takes an inventory of past pain in the upper back, while the question "Do you have pain in the lower part of your back?" (Q25) comprises pain **now** in the lower back not including the sacral region which is an area of taboo. Consequently back pain "in the last two weeks" may have been underestimated.

Checking by the author and his colleagues during house to house visits revealed that eight (32%) of the twenty-five completed questionnaires from the first trial run executed on October 1, 1982, did not qualify as the answers recorded by the PHWs did not correspond with the results during the author's home visit. A thorough discussion disclosed that most problems were

clerical in nature and some due to misinterpretation or misrepresentation of the questions by the PHWs. Understanding of the questions by the respondents was dependent on the use of the right local vocabulary by the PHWs. A second trial run of another twenty-five questionnaires still contained six (24%) of the questionnaires having to be discarded because of inaccuracies. The third trial run of fifty questionnaires comprised 10% unsatisfactorily completed questionnaires. The fourth or final trial run of one hundred questionnaires provided ninety-seven completed questionnaires with answers that conformed well with the answers given to the author during on the spot checking. As the results of the trial runs showed a prevalence rate of musculoskeletal pain of more than 45% at the time of the survey and checking on the spot revealed that quite a number of these respondents were suffering from paraesthesia and hyperaesthesia and in fact not from joint pain, the PHWs were explicitly instructed to exclude these symptoms after a neurologist had verified that they were the result of vitamin B1 deficiency.

The trial runs lasted from the first to the last of October, 1982. After the last trial run the PHWs performance was considered satisfactory and the full-scale study was launched on November 1, 1982. Following Dr. Muirden's suggestion that the phase two questionnaire could well be applied by laymen, two senior high school students were given the same course of instructions and similar discussions after checking on the spot of the completed questionnaires. However, the third trial run of one hundred questionnaires still contained 30% unsatisfactorily completed questionnaires, which was considered unacceptable. It was already very difficult for the paramedical professionals (PHW) to differentiate between joint pain and symptoms of thiamine deficiency. For the lay person this was impossible. The idea that a lay person could apply the phase two questionnaire was therefore abandonned.

Table 3.3

FLOW SHEET PILOT STUDY OF THE PHASE TWO QUESTIONNAIRE

- Hamlet household register checked with the village office registry
- Two sessions of instruction of two hours each for the PHWs on the application of the questionnaire
- First trial run of twenty-five questionnaires obtained by house to house visit by the PHWs
- Checking of the completed questionnaires by the author and colleagues by house to house visit
- Round table discussions by the author and the PHWs on the inaccuracies and errors
- Second trial run of fifty questionnaires by the PHWs followed by the same sequence of house to house checking by the author and discussions with the PHWs on the inaccuracies
- Final trial run of 100 questionnaires by the PHWs
- House to house checking of the completed questionnaires by the author
- Final discussions of the author with the PHWs on the inaccuracies and errors detected.

3.5.0 Radiological assessment

For convenience and to save time one portable X-ray unit was used for taking pictures of the hands and the other one for the forefeet. One radiographer and three assistant radiographers served the X-ray units. One diesel operator took care of the diesel generator, which generated the needed power. Where indicated posterior-anterior (p.a.) films of the knees, pelvis, p.a. and lateral films of the neck and lumbar vertebrae were taken.

Radiology was restricted to the hands and feet for financial and ethical reasons. Furthermore the portable X-ray units and unstable electrical voltage limited the possibility of X-raying the large and axial joints.

The DIP, PIP, MCP, CMC-I, CMC-lateral, carpal, wrist, and TMT, MTP-I, MTP-lateral, and PIP joints of the feet were consid-

ered as one group. In reading the films left and right side were taken together. Severity of abnormality was graded from 0 - 4: 0 indicates no abnormality, 1 is doubtful, 2 mild but definite, 3 moderate and 4 severe abnormality. The most severely affected joint in each group determined the grading for that group. The Atlas of Standard Radiographs of Arthritis was used as a reference (3.2).

In the present survey all the X-ray films were read by one observer (H.A. Valkenburg). As this observer has been involved in the X-ray analysis of most of the epidemiological surveys on rheumatic conditions in developing countries, interpopulation differences are less likely to be due to observer variations.

3.5.1 Radiological osteo-arthrosis

Radiological osteo-arthrosis was graded as follows:

Grade 1 : - Small single osteophyte without narrowing of joint space or subchondral sclerosis.
- Narrowing of joint space without osteophyte formation or subchondral sclerosis.

Grade 2 : - Bigger osteophytes
- Two or more small osteophytes at one joint site
- Single osteophyte with joint space narrowing or subchondral sclerosis.

Grade 3 : - Multiple osteophytes with obvious joint space narrowing or subchondral sclerosis or early joint destruction.

Grade 4 : - Joint destruction, subluxation, loss of joint space and gross osteophytes.

3.5.2 Radiological erosive arthritis (EA)

Radiological rheumatoid arthritis was graded as follows:

Grade 1 : - Perceivable joint space narrowing without subchondral sclerosis and osteophyte formation or
- Subluxation without other abnormalities or
- Small single erosion.

Grade 2 : - Multiple erosions at different sites or
- Single bigger erosion with or without joint narrowing.

Grade 3 : - Multiple bigger erosions at different sites with

joint space narrowing and subluxation.

Grade 4 : - Gross joint destruction with subluxation and ankylosis.

3.6.0 Rheumatoid factor test and uric acid determination

Serum was stored at minus 20 degrees Celsius in a freezer. Packed in dry ice the serum was later transported to Rotterdam for determinations of rheumatoid factor by means of the Latex Fixation Test (3.3) and the Human Erythrocyte Agglutination Test (3.4) and for Uric Acid (3.5).

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CHAPTER IV
RESPONSE RATE

4.1 Phase two

Four thousand six hundred and ninety-three people fifteen years and older were officially registered in the household registry of the ten, six and two hamlets in the villages Duren, Bandungan and Kenteng respectively (4.1). Of these, 4,683 subjects were interviewed by the PHWs and the data analysed (table 4.1). Of the ten people not surveyed, two refused to be bothered for religious reasons, two were non-communicative because of psychiatric disorders and six had not returned from absence during the period of the survey. Due to the tenacity of the PHWs, who were willing to pay a second, third, fourth and in one case a fifth visit in order to find the missing person, a high response rate of 99.8% was achieved. It should be realized, however, that most likely somewhat more people were living in the area than officially had been listed in the registry.

All the 4,683 photocopies of the completed phase two questionnaires were sent to Rotterdam, the Netherlands, for analysis and the results presented here.

Of the 1,107 respondents with musculoskeletal complaints within two weeks from the day of the interview, 841 were selected for phase three as cases. Two hundred sixty-six subjects were excluded because they either had lost their joint and/or neck and/or back complaints at the end of the phase two survey and/or because they were evidently suffering from thiamine deficiency with symptoms of hyperaesthesia and paraesthesia in the limbs, which symptoms were interpreted as joint complaints by the PHWs but were excluded by the author as cases. For controls 421 age- and sex-matched respondents who never had musculoskeletal pain were selected. The target population for phase three therefore consisted of 1,262 people (table 4.1) in a case-control study design.

Table 4.1 Attendance rates in various phases

Phase	Two		Three		Four	
	n	(%)	n	(%)	n	(%)
Target population	4693	(100)	1262	(100)	1221+	(100)
Died, migrated	-		79	(6.3)	86	(7.0)
Non-response	10	(0.2)	4	(0.3)	189	(15.5)
Seen	4683	(99.8)	1179	(93.4)	946	(77.5)

+thirty-eight people who left the village between phases two and three had returned in phase four.

Table 4.2 Reasons for non-attendance among cases and controls in phases three and four

	Three				Four			
	Cases		Controls		Cases		Controls	
	n	%	n	%	n	%	n	%
Died	24	(2.9)	11	(2.6)	25	(3.2)	10	(2.6)
Migrated	22+	(2.6)	16+	(3.8)	22	(2.8)	15	(3.8)
Absent	2	(0.2)	3	(0.7)	10	(1.3)	4	(1.0)
Psychosis	-		1	(0.2)	-		-	
Eligible	793	(94.3)	390	(92.7)	736	(92.8)	361	(92.6)
Total	841		421		793		390	

+ returned to village in phase four

4.2 Phase three.

The selected target population for phase three consisted of 841 cases and 421 controls. Due to the time lag of twenty months between phases two and three 1,183 of the 1,262 remained for follow-up in phase three. In the controls the losses were due to migration (sixteen), death (eleven), psychosis (one), and absence

(three). Of the cases, twenty-two had moved, twenty-four did not survive the interval of twenty months and two were absent (table 4.2). The differences in losses between cases and controls were insignificant. A response rate of 93.4% (table 4.1) was achieved for phase three.

4.3 Phase four

The interval of thirteen months between phases three and four resulted in proportional losses of cases and controls as compared to the period of twenty months between phases two and three. Of the 390 controls seen in phase three, twenty-nine subjects were lost of whom fifteen had moved, ten had died, and four were absent. The sixteen controls who migrated in phase two from the area returned before phase four was started. Of the 793 cases, fifty-seven were lost comprising of twenty-two who had moved, twenty-five who had died and ten who were absent (table 4.2). The twenty-two cases who had migrated in phase two from the village had returned before phase four was started. As in phase three, a higher percentage of controls than cases had moved, but more cases than controls had died. More cases than controls were absent (table 4.2).

The total number of respondents X-rayed, physically examined and from whom blood samples were taken was 946. Of these 916 proformas (table 4.3) were analysed for reasons that of thirty respondents either their X-ray films or bloodsamples were missing. Only 874 respondents seen in successive phases could be matched by identification (ID) number and sex. Among others this loss of complete follow-up was caused by thirty-eight respondents who were present in phase two but were absent in phase three but were present again in phase four. These were the sixteen controls and twenty-two cases who had moved away in phase two and were back again in the area in phase four (table 4.2).

The relatively great reduction between the number of people seen in the various phases and the final number analysed were largely due to administrative errors. Some proformas (87) from phase two and sixty-one from phase three were left with the respondents and could not be retrieved. Due to problems with the ID numbering for seventy people from phase two and fifty-one from

Table 4.3 Losses due to non-response, data information and missing match among eligible cases and controls in various phases of the study

	Phase 2		Phase 3		Phase 4	
	n	(%)	n	(%)	n	(%)
Eligible	1262	(100.0)	1183	(100.0)	1135	(100.0)
Non-response	-		4	(0.3)	189	(16.7)
Seen	1262	(100.0)	1179	(99.7)	946	(83.3)
Loss of data information	87	(6.9)	61	(5.2)	30	(2.6)
Analysable	1175	(93.1)	1118	(94.5)	916	(80.7)
No match due to non-response in phase 4	189	(15.0)	189	(16.0)	-	
New respondents	4	(0.3)	4	(0.3)	4	(0.3)
No match in phase 3/4	70	(5.5)	-		-	
No match in phase 2/4	-		51	(4.3)	-	
Matched between phase 2/4	912	(72.3)	-		912	(80.4)
No match in phase 3	38	(3.0)	-		38	(3.4)
Matched in 3 phases	874	(69.3)	874	(73.9)	874	(77.0)

phase three no age- and sex-corresponding respondent was found in the other data sets (table 4.3). In relation to the eligible number of respondents for each phase the final response rate varied between 69% and 77% for people seen in all phases and between 72% and 80% for people with complete data in phases two and four.

With the possible exception of the 189 non-respondents in phase four there is no reason to believe that the other losses were biased. Thus the response rates for people seen varied between 83% and 100%; the analysable proforma rates between 81% and 95% and the matchable rates between 72% and 80% for respect-

ively phases two and four. The unweighted mean of the three types of response rates is 87%.

The 912 respondents comprising of 620 cases with rheumatic complaints and 292 controls who matched by ID number and sex between phases two and four were used for further analysis. Phase three was not included in the analysis for reasons that its examination grid (except for bony swelling of the knees) essentially was duplicated in phase four. The other relevant findings from phase three were transferred to the phase four data base for final analysis.

Table 4.4 Loss of information among cases and controls in various phases of study

	Cases		Controls		Totals	
	n	%	n	%	n	%
Phase 2						
Selected	841	(100.0)	421	(100.0)	1262	(100.0)
Loss of information	33	(3.9)	54	(12.8)	87	(6.9)
Analysable	808	(96.1)	367	(87.2)	1175	(93.1)
Phase 3 (table 4.3)						
Eligible	793	(100.0)	390	(100.0)	1183	(100.0)
Loss of information	30	(3.8)	35	(9.0)	65	(5.5)
Analysable	763	(96.2)	355	(91.0)	1118	(94.5)
Phase 4 (table 4.3)						
Eligible	758	(100.0)	377	(100.0)	1135	(100.0)
Not analysed	137	(18.1)	82	(21.7)	219	(19.3)
Analysable	621	(81.9)	295	(78.3)	916	(80.7)
Unweighted mean loss of information		8.6%		14.5%		10.6%

For the 916 analysable subjects the losses between phases two and four of cases and controls were 8.6% and 14.5% respectively (table 4.4). In all phases of the study there was significantly more loss among controls than among cases.

Table 4.5 Age and sex-specific loss of respondents between phases two and four among cases and controls

Age	15 - 24 n (%)	25 - 34 n (%)	35 - 44 n (%)	45 - 54 n (%)	55 - 64 n (%)	65 + n (%)	total n (%)
Men							
Controls							
Phase 2	14 (9)	24 (15)	26 (16)	47 (30)	30 (19)	16 (10)	157 (99)
Phase 4	5 (4)	18 (15)	24 (20)	38 (32)	23 (19)	12 (10)	120 (100)
Losses	9 (64)	6 (25)	2 (8)	9 (19)	7 (23)	4 (25)	37 (23.6)
CF	132.6	26.3	12.7	5.6	4.6	5.9	15.3
Cases							
Phase 2	17 (5)	39 (11)	57 (16)	102 (29)	77 (22)	60 (17)	352 (100)
Phase 4	8 (3)	23 (9)	45 (17)	83 (33)	59 (23)	37 (15)	255 (100)
Losses	9 (53)	16 (41)	12 (21)	19 (19)	18 (23)	23 (38)	97 (27.6)
CF	2.1	1.7	1.3	1.2	1.3	1.6	1.4
Women							
Controls							
Phase 2	27 (13)	31 (15)	48 (23)	52 (25)	38 (18)	14 (7)	210 (101)
Phase 4	21 (12)	27 (16)	39 (23)	46 (27)	30 (17)	9 (5)	172 (100)
Losses	6 (22)	4 (13)	9 (19)	6 (12)	8 (21)	5 (36)	38 (18.1)
CF	38.8	18.9	8.3	4.7	3.6	7.8	11.9
Cases							
Phase 2	37 (8)	74 (16)	88 (19)	124 (27)	93 (20)	40 (9)	456 (99)
Phase 4	25 (7)	57 (16)	75 (21)	100 (27)	81 (22)	27 (7)	365 (100)
Losses	12 (32)	17 (23)	13 (15)	24 (19)	12 (13)	13 (32)	91 (20.0)
CF	1.5	1.3	1.2	1.2	1.1	1.5	1.2

CF = conversion factor = factor with which observed nominatorsamong cases and controls in phase four (total n = 912) should be multipliedto obtain age- and sex-specific nominator in original phase two population(n = 4683).

The age-, sex- and status-specific losses of respondents between phases two and four were not randomly distributed (table 4.5). The losses were greater among men, in the agegroup under thirty-five and over sixty-five years and among cases. A higher death rate among the cases of sixty-five years and over may have affected the prevalence rate of certain categories of rheumatic diseases known to have a decreased lifespan in developed countries (4.2) and which possibly might have caused selective mortality in our study (4.3).

4.4 Conversion to the original population sample

The losses of respondents between phases two and four were higher in men (26.3%) than in women (19.4%). For both sexes it was 22.4% (table 4.5). From the age, sex, and case-control status-specific losses a conversion factor could be calculated with which the observed phase four prevalence nominators in each age- and sex-specific subgroup had to be multiplied in order to obtain the nominator for the corresponding age- and sex-specific group in the original sample of 4,683 respondents. Although age- and sex-specific differential losses were observed, it was assumed that these would not greatly influence the original prevalence rates for disease entities, particularly because the multiplication factors were relatively constant over the age-groups where most rheumatic conditions occur.

References

4.1 Stratified data collection of the community health center subdistrict Bandungan; 1982.

4.2 Mitchell DM, Spitz PW, Young DY. Survival, prognosis and causes of death in rheumatoid arthritis. Arthritis Rheum 1986;29:706-714.

4.3 Moolenburgh JD. Rheumatoid arthritis in Lesotho. MD thesis Erasmus University Rotterdam 1984:133-138.

CHAPTER V
RHEUMATIC COMPLAINTS AND DISABILITY

5.1 Prevalence of current complaints

The frequency of peripheral joint pain currently was 16.8% among men and 18.7% among women (table 5.1). It increased with advancing age and reached values of 46.5% in the age-group of over 65 years. Women suffered slightly more from peripheral joint pain than men in all age-groups. Of those with joint pain now, 22.1% suffered of it for more than six weeks, which suggested a chronic nature of their rheumatic condition (table 5.2). Chronic rheumatic disease occurred in about 4% of all adults (table 5.1), reaching a rate of 16.6% among the aged.

Pain due to injury was rare and occurred in 1.1% (table 5.1). Of the thirty-two men with pain after injury, 71.9% and of the twenty-one women, 47.6% said this was due to work. Women had more than twice as much pain (47.6%) after injury due to traffic accidents than men (21.9%) (table 5.2), which corresponds with the fact that more women than men were transporting agricultural products to the market. They are therefore more exposed to the risk of being hit by a vehicle, and develop more aches and pains due to overloading of their back and neck.

Neck pain was present in 4.8% and was somewhat more prevalent in women (5.2%) than in men (4.4%). Women are transporting goods by means of a cotton band strapped diagonally over the shoulders (fig. 11.2). Although this may be considered a risk factor for neck pain as the load is pulling on one side of the shoulders, it can hardly explain the small difference in prevalence rate with the men. A restricted range of neck movements was recorded in 0.6% of the population sample and was again more prevalent in women. Severely restricted movement of the neck was encountered in thirteen women and in only three men.

Upper back pain was present in 5.4% and lower back pain in 15.1% of those interviewed (table 5.1) and was more prevalent among men. Back pain at any site was found in 18.2% of the men and 13.6% of the women. Of those with lower back pain now, the pain was referred to the legs and feet in 56.9%. Limitation of

Table 5.1 Age- and sex-specific prevalence of rheumatic complaints and conditions in 2,184 men and 2,499 women fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Total men	680	512	361	317	183	131	2184
Present pain							
Joint pain	4.3	11.9	17.5	28.7	35.0	45.8	16.8
Pain > 6 weeks	1.0	1.2	4.2	6.6	9.8	19.1	4.2
Pain due injury	0.9	0.2	2.2	1.9	2.7	4.6	1.5
Neck pain	0.4	2.0	5.5	7.9	10.4	15.3	4.4
Back pain	5.4	13.7	20.2	31.2	30.1	48.1	18.2
Upper back pain	2.1	2.7	4.4	8.2	14.8	20.6	5.7
Lower back pain	4.7	12.9	20.0	30.0	29.0	46.6	17.4
Referred pain	1.9	6.3	0.9	10.0	15.9	32.1	9.4
Crepitus	1.2	4.3	4.7	6.0	5.5	8.4	4.0
Pain at any site	7.5	19.5	27.7	39.7	44.8	57.3	24.5
Total women	851	585	412	339	202	110	2499
Present pain							
Joint pain	4.6	13.5	22.1	37.2	39.6	47.3	18.7
Pain > 6 weeks	0.6	1.9	4.1	8.0	8.4	13.6	3.7
Pain due injury	0.2	0.7	1.2	1.5	1.5	1.8	0.8
Neck pain	1.3	2.6	5.6	10.1	10.9	20.0	5.2
Back pain	3.9	10.1	14.8	22.4	35.1	35.5	13.6
Upper back pain	1.2	3.2	4.9	8.3	14.4	18.2	5.0
Lower back pain	3.6	9.7	14.3	21.5	33.7	34.6	13.1
Referred pain	2.0	4.8	6.8	15.3	22.3	25.5	7.9
Crepitus	1.8	1.9	3.6	5.3	4.5	10.0	3.2
Pain at any site	6.7	17.8	26.9	42.8	47.0	55.5	22.9

the range of back movements was observed in 0.3% of the people (table 5.2). Four men and three women could not move their back at all. At the time of the investigation low neck and back pain

Table 5.2 Rheumatic complaints and conditions within six weeks of the interviews in 4,683 people fifteen years and over (in percentages)

	Males		Females	
	Absolute	Relative	Absolute	Relative
Joint pain within 2 weeks	16.8	100.0	18.7	100.0
following injury	1.5	8.7	0.8	4.5
Joint pain following injury	1.5	100.0	0.8	100.0
due to work	1.1	71.9	0.4	47.6
due to transport	0.3	21.9	0.4	47.6
Joint pain last 6 weeks	4.2	25.1	3.7	19.7
Neck pain currently	4.4	100.0	5.2	100.0
restricted neck movement	0.4	9.4	0.7	13.9
Back pain currently	18.2	100.0	13.6	100.0
restricted back movement	0.3	1.8	0.3	2.1

were more often present than upper neck and back pain (table 5.3). Taking all possible locations together 24.5% of the men suffered from pain at any site, while 22.9% of the women did so (table 5.1).

The question on morning stiffness was wrongly asked by the PHWs and misunderstood by both the PHWs and the respondents. It was therefore not analysed. Crepitus of the joints was reported by only 3.6% of the people surveyed. This figure possibly is an

Table 5.3 Distribution of upper and lower neck and back pain currently in 4,683 people fifteen years and over (in percentages)

	Upper only	Lower only	Upper+ Lower	Total Upper	Total Lower
Neck	0.1	2.4	2.9	3.0	5.3
Back	0.9	10.6	4.9	5.8	15.5

underestimate as cracking of one's joints is so commonly enjoyed by Indonesians that they may consider this a normal feature of their joints.

5.2 Prevalence of past complaints

The history of past pain in the peripheral joints (appendix 2), neck and back was unreliable as the majority of such musculoskeletal complaints likely were trivial, mostly forgotten and not recalled at the time of the interview. Even past dramatic events such as a melaena or haematemesis were often forgotten (5.1). The prevalence rate of past pain is thus not suitable for comparison with other population surveys.

After rechecking on the spot by the author it was clear that past hip pain had been over-reported due to the fact that it was considered a taboo for the local custom to point to the lower back. It was therefore likely that an unknown proportion of the respondents had indicated the hip as a pain site instead of the low back and that this had been marked as such by the PHWs in the mannekin. This may have resulted in under-reporting of low/middle back pain currently in favour of hip pain in the past.

The frequency of past pain in the big toe was equal in both sexes (table 5.4). In the majority of the people the pain had disappeared within two weeks. Redness or warmth were more frequently reported by the men than by the women. Pain, swelling and redness of the big toe with the pain disappearing within two weeks occurred in three men and one woman, which suggested the presence of acute gouty arthritis in four people of the population sample at the time of their interview. All the cases of probable acute gouty arthritis in the men occurred in the age-groups 55 - 64 and 65 years and over.

Table 5.4 Past rheumatic complaints and conditions in 4,683 people fifteen years and over (in percentages)

	Males		Females	
	Absol.	Relat.	Absol.	Relat.
Pain in big toe	2.4	100.0	2.5	100.0
Big toe swelled with the pain	0.5	20.8	0.1	4.8
Big toe red with the pain	0.4	17.0	0.2	6.3
Big toe pain gone in two weeks	1.2	50.9	1.8	71.4
Peripheral joint pain	21.8	----	33.0	----

Knees, shoulders, hips and ankles were the most frequently involved joint sites in the past (table 5.5). In both men and women the right-sided joints were more frequently affected. Joint swelling in the past was recorded in very few people. The highest prevalence was observed for men in the big toe, followed

Table 5.5 Location of past rheumatic complaints recorded in the mannekin in 4,683 people fifteen years and over (in percentages)

Joint	Right only	Left only	Right+Left	Total
DIP	0.8	0.4	1.3	2.5
PIP	0.6	---	2.6	3.2
MCP	1.1	0.6	2.0	3.7
Wrist	2.2	1.1	3.4	6.7
Elbow	2.9	1.2	3.7	7.8
Shoulder	3.3	1.5	5.9	10.7
Hip	1.6	1.7	6.7	9.9
Knee	2.8	2.0	10.0	14.8
Ankle	1.9	1.4	6.0	9.3
MTP	0.6	0.5	2.1	3.2
PIP	0.4	0.3	1.6	2.3
DIP	0.3	0.4	1.6	2.3

by the ankle and the knee joint. Relapses of pain after injury occurred in 68.8% of the men and in 95.2% of the women. Past pain of the neck and the back were not recorded in the mannekin because of mistaken instructions of the questionnaire. As the history of past musculoskeletal pain was considered unreliable, the age-specific rates of pain ever in the peripheral joints were not calculated.

5.3 Disability

Although severe rheumatic diseases can be fatal, their main impact is on the quality of life and on the economic productivity. One of the major consequences of rheumatic diseases is disability, which has been defined by WHO (1980) as: "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for the human being".

As a result of pain 2.2% of the women and 3.4% of the men were disabled (tables 5.6 and 5.7). The total disability rate was 2.8% of which 78.3% was below 65 years. Of the seventy-four men and fifty-five women with disability 78% had peripheral joint pain and 80% of the men and 62% of the women had back pain. Neck and upper back pain were less often associated with disability than peripheral joint pain. Being unable to lift was strongly related to joint and low back pain. Disability in dressing and carrying was most often associated with peripheral joint pain.

Table 5.6 Age- and sex-specific distribution of any disability in 4,683 people fifteen years and more (in percentages)

Agegroups	15-24	25-34	35-44	45-54	55-64	65^{+}	Total
Men + Women	1531	1097	773	656	385	241	4683
Any disability	0.3	0.9	2.6	4.9	9.0	11.6	2.8

Since the total population survey was carried out by house to house visits and most houses consisted of one big space which

served as a living, dining and bed room, the likelihood that people with severe disability were kept away by their relatives and would have escaped detection by the PHWs was small.

Table 5.7 Disability in relation to peripheral joint, neck and backpain in 2,184 men and 2,499 women fifteen years and over

Not able to	Dress	Walk	Carry	Lift	Total
Men number	12	21	28	62	74
Absolute percentages	0.5	1.0	1.3	2.8	3.4
			Relative percentages		
Peripheral joint pain	91.7	71.4	89.3	83.9	78.4
Neck pain	41.7	9.5	28.6	37.1	32.4
Upper back pain	16.7	19.0	32.1	29.0	29.7
Low back pain	58.3	52.4	25.0	92.3	64.9
LBP + upper back pain	58.3	61.9	71.4	94.2	79.7
Women number	12	20	25	48	55
Absolute percentages	0.5	0.8	1.0	1.9	2.2
			Relative percentages		
Peripheral joint pain	58.3	60.0	68.0	81.3	78.2
Neck pain	50.0	45.0	44.0	35.4	32.7
Upper back pain	8.3	20.0	20.0	22.9	21.8
Low back pain	41.7	50.0	56.0	64.6	61.8
LBP + upper neck pain	41.7	50.0	56.0	60.4	61.8

LBP = low back pain

Of the seventy-four men and fifty-five women with pain and any type of disability 78.4% men and 73.2% women had to stop work; in particular those who could not lift, and to a lesser extent those unable to walk and carry (table 5.8).

Table 5.8 Type of disability in relation to work capacity (in percentages)

Unable to	Had to stop work	
	Men	Women
dress	41.7	41.7
walk	61.9	55.0
carry	60.7	60.0
lift	79.0	79.2
Any action	78.4	73.2

Table 5.9 Coping strategies for rheumatic complaints of 2,184 men fifteen years and over

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Total men	680	512	361	317	183	131	2184
	Absolute percentages						
Needs treatment	6.8	19.5	29.6	39.4	43.2	55.7	24.3
	Relative percentages						
Been to doctor	21.7	13.0	25.2	25.6	34.2	26.0	24.3
Been to nurse	28.3	43.0	54.2	56.0	57.0	61.6	50.3
Been to PHW	8.6	4.0	10.3	11.2	13.9	12.3	9.8
OHC*	39.1	45.0	64.5	65.6	75.9	68.5	60.8
Been to							
Healer	15.2	16.0	11.2	9.6	25.3	9.6	13.9
Acupuncturist	4.3	2.0	4.7	8.0	12.7	6.8	6.6
Masseur	45.7	5.0	52.3	61.6	58.2	45.2	53.5
Self-medication	45.7	47.0	56.1	64.0	58.2	52.1	55.2
Used herbs	34.8	52.0	45.8	52.0	46.8	43.8	47.3
THC‡	84.8	87.0	83.2	85.6	94.9	84.9	86.4

* = official health care utilization

‡ = traditional health care utilization

5.4 Utilization of official and traditional medical services

The question on whether the respondents needed help or treatment was asked to both the respondents with present and past musculoskeletal pain. Ninety percent said they needed treatment. Of these more than 60% had visited either the community health center or a medical doctor, nurse or PHW. In absolute percentages 14.6% of this population used the official health care system for their rheumatic complaints. There were slight differences in the utilization patterns between the various age-groups (tables 5.9 and 5.10).

Table 5.10 Coping strategies for rheumatic complaints of 2,499 women fifteen years and over

Agegroups -	15-24	25-34	35-44	45-54	55-64	65+	Total
Total women	851	585	412	339	202	110	2499
	Absolute percentages						
Needs treatment	7.1	18.3	28.2	43.1	47.5	53.6	23.4
	Relative percentages						
Been to doctor	28.3	23.4	21.6	25.3	26.0	28.8	24.8
Been to nurse	45.0	49.5	54.3	59.6	51.0	62.7	54.3
Been to PHW	0.0	7.5	9.5	7.5	12.5	15.3	8.6
OHC*	50.0	55.1	63.8	66.4	67.7	64.4	62.0
Been to							
Healer	8.3	5.6	7.8	12.3	10.4	6.8	8.9
Acupuncturist	6.7	5.6	5.2	8.2	8.3	6.8	6.8
Masseur	50.0	49.5	47.4	59.6	45.8	55.9	51.7
Self-medication	45.0	60.7	65.5	70.5	56.3	62.7	62.0
Used herbs	36.7	39.3	49.1	57.5	50.0	59.3	48.3
THC‡	81.7	85.0	86.2	88.4	83.3	86.4	85.6

* = official health care utilization

‡ = traditional health care utilization

Of the men and women with rheumatic complaints at any site the majority had sought help from two or more traditional health care facilities (table 5.11).

Table 5.11 Utilization of traditional health care facilities* in 534 men and 513 women fifteen years and over with rheumatic complaints (in percentages)

Number of facilities	1	2	3	4	5	None
Men	31.5	26.2	23.2	4.1	0.7	14.2
Women	28.8	27.9	25.3	4.7	0.3	12.9

* Traditional health care facilities: traditional healing, acupuncture, massage, self-medication and herbs.

Of those who needed treatment 58.7% bought over the counter whatever antirheumatic drugs were available for pain relief (tables 5.9 and 5.10). One of the most preferred drugs was a combination of five milligrams of prednison, two hundred milligrams of phenylbutazon, and three hundred milligrams of paracetamol buffered with antacids in a threelayered tablet. In absolute percentages the majority of the people with pain tried to obtain relief by self-medication (14%), massage (12.5%), and the consumption of herbal medicines (11.5%). A small minority was treated by traditional healers (2.7%) and acupuncturists (1.6%). In total 20.4% of the target population sought traditional health care relief for their pain.

Of the seventeen people with four disabilities (table 5.12) two men said they did not need treatment. Correspondingly one man with three and another one with two disabilities claimed they did not need treatment. Of the seventy-eight people with one disability two men and one woman considered therapy unnecessary. Thus of the total of 129 men and women with any type of disability, 95% expressed their need for treatment and help. After elaborate questioning by the author the surmise was confirmed that the seven disabled respondents who stated that

they did not need treatment had accepted their fate after at first they had made fruitless attempts to obtain help from every available official and traditional health care facility. Of the 4,683 people fifteen years and over, 2.8% (seventy-four men and fifty-five women) had pain and disability and of these 5.4% refused further official medical services because of frustration.

Table 5.12 Perceived need of treatment for disability in 4,683 people fifteen years and over

Number of disabilities	4	3	2	1	Any
Number of men	7	7	14	46	74
Needs treatment	71.4%	86.7%	92.9%	95.7%	91.9%
Received treatment	100.0%	100.0%	100.0%	84.4%	91.2%
Number of women	10	6	7	32	55
Needs treatment	100.0%	100.0%	100.0%	97.0%	98.2%
Received treatment	100.0%	100.0%	100.0%	83.9%	90.7%

Six men and five women with some kind of disability expressed their need for official primary health care but were not receiving it. In absolute figures 0.2% of the target population with pain and disability who needed organized medical therapy were not receiving it.

5.5 Discussion

General survey constraints

The Indonesian study differed from the original COPCORD concept in that it omitted phase one. Trial runs preceding the survey and random sample checking of the completed questionnaires by physicians succeeded in maintaining accuracy and objectivity. The interviews were done by primary health care workers instead of nurses. Four more questions on coping with pain (acupuncture (Q36), massage (Q37), self-medication (Q38) and use of herbs (Q39)) were added to the original COPCORD questionnaire and a

few English questions were unintentionally changed by the translation into Indonesian. Often the Indonesian questions had to be converted into the local dialect (Javanese). Some of the English and Indonesian words could not be translated or had no synonym in the very limited vocabulary the people were using for their daily communication. Nevertheless the English questionnaire was as properly translated as the circumstances permitted and adequately applied by the PHWs, not denying the fact that weaknesses in the questionnaire (appendix 2) itself, linguistic barriers, and problems with description of symptoms by lay people may have had some bearing on the results of the survey.

Specific survey constraints

The instructions to the questionnaire were such that on the one hand past joint pain (Q2) (including swelling, redness or warmth) had to be recorded on the mannekin, and on the other hand current neck and middle backpain (Q19 and 27). This was confusing for the PHWs. The questions whether the past joint pain followed injury (Q5) and relapsed again (Q9) were cryptic in that no time interval was mentioned between the initial event and the second attack of pain. In some instances the injury had occurred thirty to fourty years before, which made it unrealistic to relate present joint pain to the past accident.

With regard to the question on swelling of the big toe (Q11) confusion with hallux valgus and bunions could have easily occurred. Redness of the skin could have been missed in dark skinned people. In acute gouty arthritis, the skin overlying the affected joint does not turn red, but only darkens in colour and becomes shiny.

The questions on morning stiffness (Q14 and Q15) were neither understood by the PHWs nor by the people. The local Javanese dialect does not have a word for it. Valkenburg (5.2), Muller (5.3) and Moolenburgh (5.4) had a similar experience in Africa. Very few of the villagers owned a clock or a watch and were unable to estimate the time (Q15a, Q15b). Passing water and dressing took less than one minute to accomplish as toilet facilities were a few steps away from the house and wearing one layer of cloth did not require more than one minute to dress. Almost none of the villagers had breakfast (Q15c). Questions

15a, 15b and 15c were therefore inept. Furthermore, a higher morning temperature in tropical climates could possibly influence the occurrence of morning stiffness. Grating of the joints (Q16) is a customary experience in Melanesian and Polynesian populations, where the people purposively move their joints in such a way that cracking emerges which is enjoyed when they are fatigued or drowsy, a similar practice as in stretching and yawning. The respondents possibly negated this question as they believed it to be quite normal. When queried their answer was no, but when asked to pay special attention to the sounds their joints were eliciting by letting them move their shoulder and knee joints, joint crepitus was acknowledged.

The response rate was extraordinary high at 99.8%. This could have been due to the fact that more people were living in the selected villages than officially had been registered. A new census of the target population by the research team would have offended the local dignitaries and thereby hampered with their cooperation. Response rates of up to 99.0% have also been achieved in earlier population interview surveys by means of questionnaires on rheumatic disease (5.5).

As the protocols used for the Indonesian, the Philippines (5.6 and 5.7) and the UK surveys (5.5) were different, their results are not comparable. Next to applying a different questionnaire, the EPOZ study (5.8) in Holland covered people twenty years and older. Comparing the age- and sex-specific prevalence rates of musculoskeletal pain present at the time of the survey, the rates for the 25 - 65+ years age-groups for men are remarkably similar (table 5.13), but differ more than 10% between the women (table 5.14). However the differences were not significant. In a recent Canadian survey on rheumatic complaints the rate for men and women together was 20.6% (5.9). Notwithstanding the similarities between populations it should be realized that differences in design and observers could easily have influenced the results. On the other hand it is conceivable that musculoskeletal complaints are ubiquitous and that in this respect people around the world react the same way where perceived joint pain is concerned. Unless the same protocols and questionnaires are used it remains uncertain whether pain rates differ between populations or not. A standardized COPCORD

protocol eventually would meet this problem, provided the complaint threshold of the different populations is identical.

Table 5.13 Age- and sex-specific pain rates at any site in different populations in men (in percentages)

Age	Indonesia	Philippines(5.4)	U.K.(5.5)	EPOZ Holland(5.8)
15-24	8	8	9	0
25-34	20	25	20	23
35-44	20	41	19	26
45-54	40	45	33	38
55-64	45	56	47	39
65 +	57	69	39	30
15-65+	25	27	28	--
25-65+	31	34	32	31
15-65+ M+F	24	29	33	--
25-65+ M+F	31	36	38	36

M + F = males + females

To illustrate this latter point we can look at the complaint rate of musculoskeletal pain in Japan. In a study of 7,364 people the total current rheumatic pain rate was 10.3% (5.10), which is very low when compared to the other countries presented in tables 5.13 and 5.14. This low rate could be the result of the samurai (historical Spartan or austere) culture in which it is considered a disgrace to complain about trivial musculoskeletal aches and pains. On the other hand the total current rate of rheumatic complaints among 299 English foundry workers of 35 - 74 years was 26.8%, while the expected rate was 35.8% (5.11). The radiant heat of the foundry and the low humidity were thought to have raised the pain threshold with resultant less rheumatic complaints. The relatively cold climate of Bandungan could then account for the higher complaint rate. There were no significant differences in the pain rates of the individual pain sites

between the Indonesian phase two and the Philippines phase one COPCORD study, except for lumbar pain (table 5.15).

Table 5.14 Age- and sex-specific pain rates at any site in different populations in women (in percentages)

Age	Indonesia	Philippines(5.6)	U.K.(5.5)	EPOZ Holland(5.8)
15-24	7	15	9	--
25-34	18	30	16	24
35-44	27	25	32	32
45-54	43	47	41	50
55-64	47	49	63	54
65 +	55	56	52	51
15-65+	23	30	38	--
25-65+	31	38	43	41

The Indonesian farmers had a low back pain rate of 15.1%, which is comparable to the Canadian survey, while the Filipinos expressed low back pain in only 7.5%. This could eventually be accounted for by the fact that Indonesian rice farmers are more involved in hoeing than the Filipino coconut farmers and wood cutters.

Table 5.15 Age- standardized comparison of pain rates in various sites in the Indonesian and the Philippines COPCORD surveys (in percentages)

Pain site	Indonesia Phase 2	The Philippines Phase 1
Neck	4.8	5.1
Upper back	5.3	5.5
Lower back	15.1	7.5
Peripheral joint	17.8	18.2
Total pain rate	23.6	28.4

Respondents with paraesthesia and hyperaesthesia due to thiamine deficiency were excluded from the analysis. These are very common symptoms in developing countries where the main staple food consists of milled or stamped rice or food containing thiaminases. This may considerably raise the prevalence rate of musculoskeletal pain when included.

The disability rate was low the way it was defined (2.8%). It only concerned dressing, lifting, carrying and walking and lacked other activities of daily living. Most likely no cases of severe disability were missed by the PHWs as the interviews were carried out by means of home visiting and obtained a very high response rate. It was unfortunate that the inventory of disabilities in the Philippines and in Indonesia was not done in an identical way, making it impossible to compare the rates in both studies. Being unable to dress and to lift were not asked for in the Philippine survey and unable to hold was not mentioned in the Indonesian questionnaire. Nevertheless the total disability rate was similar in the Philippines (4.6 and 4.7) and Indonesia (table 5.16).

Table 5.16 Disability rate in the Philippine and Indonesian COPCORD surveys

Phase	The Philippines phase 1	Indonesia phase 2
Cannot dress	----	0.5%
Cannot hold	0.8%	----
Cannot stand	0.9%	0.1%
Cannot lift	----	2.3%
Cannot carry	1.5%	1.1%
Cannot walk	0.7%	1.9%
Total disability	2.7%	2.9%

A thorough interview with the marketing department of the pharmaceutical distributor concerned with the sales of the tablets containing a combination of phenylbutazon, prednison and

paracetamol disclosed an annual gross sales of thirty million US$ in Central Java. In 1982 the net price of one tablet of this drug was Rp 100.- which was equivalent to US$ 0.10. The total number of tablets sold was more than three hundred million for a total population of 24,693,796. The annual per capita consumption of the drug combination for the inhabitants of Central Java was therefore twelve tablets. The expected annual per capita consumption of the drug combination in those who had musculoskeletal pain and resorted to self-medication, without doubt was much higher as people without complaints and those fourteen years and younger presumably did not take it. Imported Chinese herb capsules, when analysed proved to contain a similar drug combination. Since the Bandungan survey combinations of corticosteroids with non-steroidal anti-inflammatory drugs have officially been banned in Indonesia by the end of 1987.

As the majority of the people (85.6%) sought the help of the traditional health care professionals such as the masseur, acupuncturist, traditional healer and herb dispenser it could be contemplated to upgrade these people in order to improve their performance concomittantly with a programme directed towards the improvement of the official primary health care system. Whether such a programme would induce a shift in the utilization of the traditional towards the official health services is questionable, particularly while in the provision of the official primary health care services much is still left to be desired. Medical and paramedical professionals in the organized primary health care system in Indonesia are not adequately trained to cope with chronic diseases and disability nor is the community health center equipped to handle these patients. In contrast to the Indonesian situation 53% of Canadian sufferers of rheumatism were seen by a physician, 34% by a chiropractor and 13% by other types of health professionals (5.9).

The COPCORD population survey was original in its design in that it developed a model in which in an efficient and inexpensive way, applying local resources and manpower, the magnitude of the problem of rheumatic diseases in the community as a whole was evaluated and individuals who were in urgent need of treatment and support and not receiving it or were inadequately treated were identified. It was an effective case

finding exercise in the population under study and relevant where limited resources and skills are available. It was feasible to collect data on rheumatic pain, disability and utilization of services in a large population sample at a minimal cost of US$ 1.28 per person unit including data management.

The WHO-ILAR COPCORD principle is to identify the patients who express a perceived need for treatment, but are not receiving it (5.12). And those individuals who are consulting the official medical health care system but are inadequately treated for reasons that the medical and paramedical professionals in developing countries have been insufficiently trained in the management of rheumatic diseases and chronic disability. The more disabled the patients are and in urgent need of help the less likely they are to be adequately treated. WHO-ILAR COPCORD stages two and three programmes would then be appropriate to correct this situation.

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CHAPTER VI
RHEUMATOID ARTHRITIS

6.1 Loss of rheumatoid arthritis to follow-up

During phase two of the population survey, thirteen respondents were suspected to be suffering from rheumatoid arthritis (RA). Three months after the completion of the phase two study these subjects were physically examined. Five of them fulfilled only three or four of the first five ARA criteria (appendix **10)** and were considered to have probable RA and not further investigated. The remaining eight with five or more ARA criteria got X-rays of the hands and feet and serum samples were obtained for rheumatoid factor testing (Latex fixation and Waaler-Rose test). Furthermore ESR and C-reactive protein were determined (table 6.1). Therefore the prevalence rate of probable and definite RA in this population was 0.3% with a sex ratio of nine females to four males.

Onset of disease in the definite cases ranged from 6 - 20 years. One patient was 26 years old, all the others were 55 years and older. Six respondents had more than one hour morning stiffness, which was very difficult to elicit from them unless it was elaborately explained. Pain of the joints at rest and on movement or on pressure was present in all eight respondents. Symmetrical swollen joints were found in all the subjects, but no one of them remembered how long the symmetrical joint swelling existed. The most frequently affected joints were the wrist, metacarpophalangeal and metatarsophalangeal joints. Rheumatoid nodules were not seen. Erythrocyte sedimentation rate was elevated in all. Grip strength was considerably reduced. C-reactive protein titer was above normal. Except one all had a positive RF test.

Radiology of the hands and feet showed grade 2 - 4 changes in all. Case no. 1, 7 and 8 showed grade four erosive arthritis (figs. 6.1A & B, 6.2A & B and 6.3A & B).

All the patients were in Steinbrocker's functional grade 3 (6.1). No synovial biopsy or fluid were obtained. Unfortunately the eight rheumatoid arthritis patients diagnosed in March, 1983

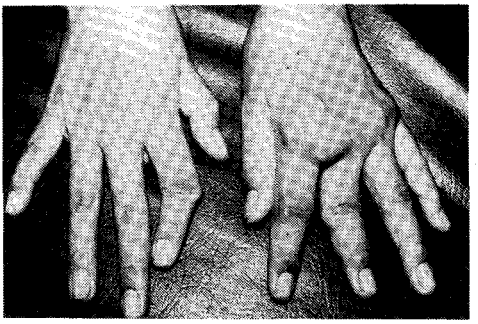

Fig. 6.1A - Case 1

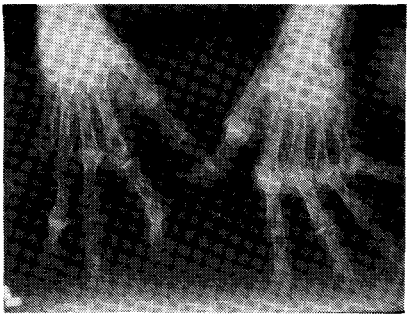

Fig. 6.1B - Case 1

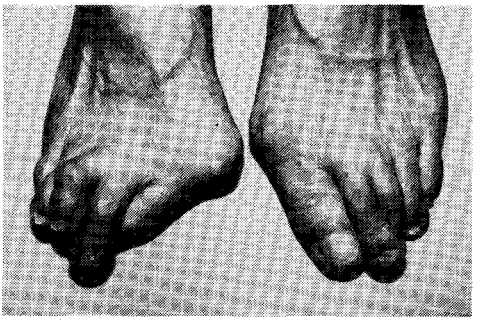

Fig. 6.2A - Case 7

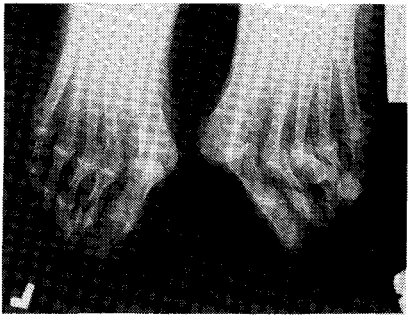

Fig. 6.2B - Case 7

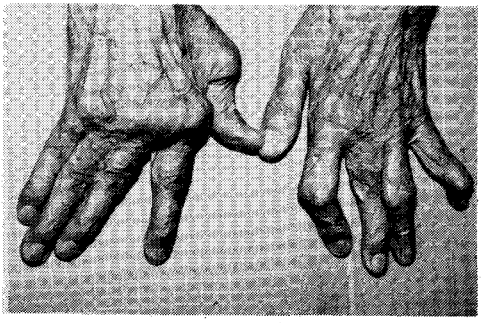

Fig. 6.3A - Case 8

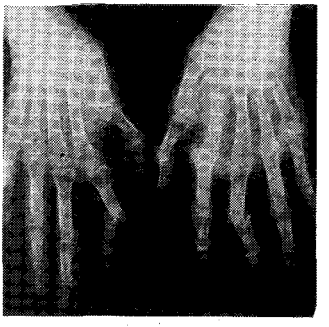

Fig. 6.3B - Case 8

Fig. 6 Rheumatoid arthritis in Bandungan

Table 6.1 Data on the eight cases of definite rheumatoid arthritis based on the American Rheumatism Association criteria

N	Age	Sex	Duration	LFT	WR	ESR	CRP	MS	GS	EA grade
1	26	F	8 years	5120	392	105	48	All day	126 mm Hg	4
2	55	M	6 years	2560	196	64	24	1/2 day	141 mm Hg	2
3	60	F	7 years	5120	48	100	48	All day	130 mm Hg	2
4	65	F	12 years	1280	-	70	24	2 hours	187 mm Hg	2
5	67	F	8 years	5120	1024	73	12	1 hour	209 mm Hg	2
6	70	M	15 years	1260	-	55	12	4 hours	175 mm Hg	2
7	70	F	10 years	10240	512	61	12	neg	134 mm Hg	4
8	80	F	20 years	-	-	84	24	neg	110 mm Hg	4

LFT = latex fixation test (positive: ≥ 640)
WR = Waaler-Rose rheumatoid factor test (positive: ≥ 32)
ESR = erythrocyte sedimentation rate
CRP = C-reactive protein (normal value: ≥ 12)
MS = morning stiffness
GS = grip strength (normal value: ≥ 200 mm Hg)

belonged to the group that did not survive the interval between phase two and four and were not seen during the January, 1986, epidemiological survey. The fate of the five probable RA cases could not be ascertained as they were not sufficiently registered to be identifiable in the later phases of the study.

Case no 8 died one year after her diagnosis was established. She succumbed after 4 days of high fever, breathlessness and chest pain with cough and reddish-brown phlegm. No clearcut history was available on the cause of death of the other seven cases except for the unmistakable involvement of fever. The most probable cause of death was pneumonia or miliary tuberculosis. Obviously rheumatoid arthritis carried a very high risk of early mortality in this population sample where infectious and parasitic diseases was rampant and diarrhoea together with malnutrition were common.

6.2 Prevalence of rheumatoid arthritis

No new cases of definite RA were encountered during the phases three and four studies of the Bandungan survey. Based on clinical judgement fourteen people had doubtful (grade 1) inflammatory polyarthritis (0.3% of the total population sample), but did not fulfill sufficient ARA criteria for probable disease. This suggests that the incidence of the disease is low, which together with a rapid and fatal course might explain the low prevalence rate of 0.2% of definite RA and 0.3% of probable and definite disease during the phase two study.

6.3 Radiological erosive arthritis

Erosive arthritis (EA) was present in 0.1% of the men and in 1.2% of the women based on the films of hands and feet obtained during the phase four study and read by H.A. Valkenburg. Together with the eight definite RA cases with radiological erosive arthritis it brings the overall prevalence rate of EA to 0.9%. In the men the affected joints were the DIP-joints (0.06%) and the lateral MTP-joints (0.06%). In the women the affected joints were the PIP's (0.10%), wrist (0.48%) and the lateral MTP-joints (0.52%).

None of the 9 respondents with EA in phase four showed sufficient signs and symptoms to be classified as probable or definite RA or past polyarthritis. They were therefore considered to be false-positive.

6.4 Rheumatoid factor

The age- and sex-specific distribution of a positive Waaler-Rose (HEAT) and Latex Fixation Test (LFT) is given in table 6.2. Contrary to the expectation a significantly higher prevalence rate was observed for the HEAT as compared to the LFT, the latter being within the limits of the 5% rate set as a maximum for normal populations.

Table 6.2 Age- and sex-specific distribution of positive Waaler-Rose (HEAT) and Latex fixation (LFT) rheumatoid factor tests in 4,683 people fifteen years and over (in percentages)

Age-group	15-24	25-34	35-44	45-54	55-64	65+	Total
HEAT							
Men							
% positive	20.9	6.2	8.7	18.7	10.0	12.3	13.7
Women							
% positive	15.2	7.9	5.9	15.8	16.7	12.1	12.0
Men + Women							
% positive	17.7	7.1	7.2	17.2	13.5	12.2	12.8
LFT							
Men							
% positive	----	----	12.7	8.4	8.4	10.4	4.7
Women							
% positive	----	0.5	----	11.5	10.2	6.0	2.8
Men + Women							
% positive	----	0.3	5.9	10.0	9.3	8.4	3.7

The reciprocal titer distribution (table 6.3) for the HEAT showed a relative increase in prevalence rate for titers 64 and 128. The association between the HEAT and LFT was poor (kappa = 0.30) suggesting an independent mechanism for their induction.

All observed positive titers in phase four could be considered to be false positive as none of them were associated with clinical parameters of rheumatoid arthritis.

Table 6.3 Reciprocal titer distribution of HEAT and LFT in 4,683 people fifteen years and over (in percentages)

HEAT titer	< 32	32	64	128	256	512	≥ 1024	
Men	86.3	0.1	5.8	5.3	0.9	0.8	0.9	
Women	87.9	0.6	3.7	5.3	1.6	0.6	0.2	
LFT titer	< 80	80	160	320	640	1280	2560	≥ 5120
Men	89.9	2.2	0.9	2.4	2.4	0.9	0.7	0.8
Women	94.0	0.5	0.9	1.9	0.6	0.7	1.5	—

6.5 Discussion

The low prevalence of definite RA is comparable to the one observed in most developing countries in Africa (6.2 - 6.5), the Philippines (6.6) and Japan (6.7), but differs from the 1 to 2% definite RA seen during population surveys in developed countries (6.8). In table 6.4 the prevalence rates for definite and probable + definite disease are presented for a number of caucasian and non-caucasian population studies. Table 6.4 suggests that the less developed the country, the rare definite RA occurs. Moolenburgh (6.25) explained this by a quickly worsening natural course and hence a high mortality in patients living in deprived situations. A number of studies in developed countries have shown an excess mortality in RA (6.26-6.39). However scrutinizing table 6.4 the varying rates of definite and/or probable RA show a considerable overlap between caucasian (developed) and non-caucasian (less developed) populations, which on the one hand might be explained by observer differences and on the other hand by differences in age composition. Moreover a number of population studies concern small sample sizes rendering large 95% confidence intervals for the observed rates.

Comparing rates for definite RA in people 55 years and over, the Indonesian prevalence was less than half the rate of the USA (table 6.5).

Table 6.4 Estimates of the prevalence rates of definite and probable rheumatoid arthritis in various adult caucasian and non-caucasian populations (in percentages)

	Number	Criteria	Definite RA	Def.& Prob. RA
Country				
Caucasian				
Sudbury, Mass., USA (6.9)	5552	ARA	0.5	2.2
Tecumseh USA (6.10)	6000	ARA	0.5	1.2
Samso(main study),Denmark(6.10)	19000	Rome	0.8	—
Samso, Denmark (6.11)	4500	Rome	0.8	—
Sweden, 5 areas (6.12)	39418	ARA	0.4-0.8	1.0-2.4
Zoetermeer (Netherlands)(6.13)	6500	ARA	0.9	2.0
HES* USA (6.14, 6.15)	6672	ARA	1.0	3.2
Leigh, England (6.16)	672	IP/ARA	1.1	4.9
Wensleydale, England (6.16)	465	IP/ARA	1.4	5.7
Non-Caucasian				
Phokeng, SA, rural (6.4)	801	NY	0.1	0.8
Liberia & Nigeria(WA),rural(6.2)	1027	ARA	0.1	0.9
Indonesia, rural	4683	ARA	0.2	0.3
Lesotho (SA), rural (6.3)	1752	ARA	0.2	1.8
Japan, Iwata, rural (6.7)	2345	ARA	0.3	—
Puerto Rico, urban (6.17)	3885	ARA	0.3	0.9
Canadian Inuit, rural (6.18)	2055	ARA	0.6	—
Canadian Haida,rural (6.19)	492	ARA	0.6	1.8
Japan, urban (6.20)	11393	ARA	0.6	—
Transkei, SA, rural (6.5)	1601	Rome	0.7	2.2
Alaskan Eskimo,rural(6.21,6.21)	1443	ARA	0.8	—
Soweto, SA, urban (6.23)	551	NY	0.9	3.3
Iraq (6.24)	6999	ARA	1.0	—

* Health Examination Survey

Table 6.5 Prevalence rate of definite RA in the U.S. Health Examination (6.14) and the Indonesian COPCORD survey among men and women 55 years and over

Country	U. S. A.		Indonesia	
	n	%	n	%
Men examined	755		314	
Definite RA	14	1.9	2	0.6
Women examined	812		312	
Definite RA	31	3.8	5	1.6

The overall prevalence rate of 1% for erosive arthritis in Bandungan is relatively low when compared with other surveys where X-rays of the hands and feet were taken. As employment in men is more varied than in women the rates for erosive arthritis of the hands in men aged 35 - 64 years are compared (table 6.6).

Table 6.6 Prevalence of erosive arthritis (EA) of the hands grade 2 - 4 in men aged 35 - 64 years in different populations (6.40) (unweighted means)

Region	Occupation	X-rayed n	EA %
Bandungan (Ind.)	farmers	272	0.4
Wensleydale (UK)	shepherds	213	1.0
Leigh (UK)	miners	429	1.8
Liberia/Nigeria(WA)	rubber tappers	208	3.8
Jamaica (WI)	cultivators	260	4.2
Arizona (USA)	cotton growers	300	4.4
Montana (USA)	ranchers	431	4.4
Queen Charlotte Isl(Can)	fishermen	97	5.1
Oberhörlen (FRG)	builders	90	5.6

Fourteen-fold differences are observed, but no distinct relation with occupation exists. EA of the feet varies even thirty-fold between populations (table 6.7). Here walking barefooted has less influence than Lawrence suggested (6.40). The differences between Indonesians and African Negroes can better be explained by racial influences.

Table 6.7 Prevalence of erosive arthritis (EA) of the feet grade 2 - 4 in men aged 35 - 64 years in different populations (6.40) (unweighted means)

Region	Footwear	X-rayed n	EA %
Bandungan (Ind.)	none	272	1.0
Wensleydale (UK)	boots	220	1.9
Leigh (UK)	clogs	430	1.2
Liberia/Nigeria (WA)	none	208	8.8
Jamaica (WI)	none	260	12.6
Arizona (USA)	moccasins	299	3.4
Montana (USA)	moccasins	430	2.6
Queen Charlotte Isl(Can)	boots	91	5.6
Oberhörlen (FRG)	boots	89	6.5

The Bandungan women aged 35 - 64 years showed grade 2 - 4 EA of the feet in 0.5% and of the hands in 1.1%. They walk also barefooted and their daily workload is comparable to that of the men. The prevalence rates of EA of the hands and the feet in African women are comparable to those observed in their male counterparts. When the prevalence rates for EA of the hands respectively the feet are compared between men and women (table 6.8) relatively small differences are observed for the hands with exceptions for the American Indians in Montana, the Canadian Indians in the Queen Charlotte Islands and the Germans, where the rates in men prevail. For the feet the major differences between men and women are observed in the Jamaican Negroes, the Arizona Indians and again the Germans. No ready explanation can be given

for these variations. Observer differences are less likely as the films were read by two observers (J.S. Lawrence and H.A. Valkenburg) who had been regularly involved in standardization procedures.

Table 6.8 Sex-specific differences in erosive arthritis (EA) grade 2 - 4 of the hands and feet in different populations aged 35 - 64 years (6.40) (unweighted means)

Region	EA - hands			EA - feet		
	men %	women %	w-m %	men %	women %	w-m %
Bandungan (Ind.)	0.4	1.1	0.7	0.4	0.5	0.1
Wensleydale (UK)	1.0	2.9	1.9	1.9	1.8	-0.1
Leigh (UK)	1.4	2.2	0.8	1.2	1.5	0.3
Liberia/Nigeria (WA)	3.8	2.8	-1.0	8.8	8.9	0.1
Jamaica (WI)	4.2	5.6	1.4	12.6	7.9	-4.7
Arizona (USA)	4.4	4.4	0	3.4	6.4	3.0
Montana (USA)	4.4	1.4	-3.0	2.6	1.5	-1.1
Queen Charlotte Isl(CAN)	5.1	1.2	-3.9	5.6	5.2	-0.4
Oberhörlen (FRG)	5.6	0.8	-4.8	6.5	1.8	-4.7

According to the ARA criteria the prevalence of rheumatoid factor (RF) should not exceed 5% in normal populations. However this rate is regularly higher for either the HEAT or the LFT in tropical countries (table 6.9). The higher prevalence for the LFT is generally explained by the presence of various parasitic infections (6.46), but an increased prevalence rate for the HEAT is mainly observed in patients with trypanosomiasis, Kala-azar and leprosy (6.41, 6.47-6.49). None of these diseases were present during the surveys in Lesotho and Indonesia. However in the Bandungan area yaws had been rather prevalent before and during the second world war, but had been eradicated by a systemic penicillin campaign. Whether this or other spirochaetal

infections could have been responsible for the great number of people with a positive HEAT remains to be investigated. It particularly can not explain the high rates among young people.

The overall suggestion which emerges from the Bandungan population survey is that RA is a relatively rare disease as is erosive arthritis. When RA occurs it may run a relatively severe course and may become superimposed by infections (mostly respiratory infections), because of the cold and damp climate these people live in without heating of their houses or proper clothing. These infections may induce an increased mortality, which together with a low incidence would explain the lack of RA cases in the phase four study. At least two cases of definite RA were expected to have been seen in phase four, but none were. For obvious reasons they could have been missed among the non-respondents.

Table 6.9 Prevalence rate of HEAT and LFT in different rural populations fifteen years and over (in percentages)

Serology	H E A T			L F T		
Region	Men	Women	Both	Men	Women	Both
Netherlands (6.41)	2.3	1.7	2.9	1.5	0.9	1.2
Israel (6.42)	0.8	1.2	0.9	3.8	3.0	3.6
England (6.43)	4.4	4.7	4.0	7.0	4.0	5.6
Nigeria (6.41)	0.7	2.3	1.5	12.0	10.7	11.4
Phokeng (6.4)	3.1	1.9	2.3	8.9	9.0	8.9
South Africa (6.44)						
Rural	3.1	1.8	2.3	8.8	9.0	8.9
Urban	1.9	5.9	3.2	11.9	12.6	12.1
Liberia (6.41)	4.1	6.2	5.1	4.5	6.2	5.3
Indonesia	13.7	12.0	12.8	4.7	2.8	3.7
Lesotho (6.45)	21.0	20.4	20.6	10.5	12.2	11.8

In all instances the same testsystems were used and for 9 surveys the tests were done in one laboratory.

On the other hand most people were quite willing to come as they at least got the benefit of receiving free medicine for their ailments.

In the last week of the phase four study the doctors made home visits in cases of non-response because of illness. Again no cases of RA were detected.

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CHAPTER VII
SPINAL DEGENERATIVE AND OTHER CONDITIONS

7.1 Introduction

The diagnosis of spondylosis (degenerative disc disease) based on clinical judgement is subject to marked interobserver variations (7.1). This is also true for the radiological diagnosis of spondylosis, albeit to a lesser degree because of the use of standardized criteria (7.2).

In this study clinical judgement of degenerative disc disease was based on a typical history such as pain in the spine at rest, on movement and on pressure, stiffness after immobility and being abolished by a few movements, and limitation of movement (7.3).

As X-ray films of the cervical, dorsal and lumbar spine, hips and knees were taken on indication only it was not possible to relate the clinical diagnosis of spondylosis and peripheral osteoarthritis (OA) of the large joints to radiological findings (7.4).

7.2 Cervical spondylosis

The diagnosis of cervical spondylosis was made when two of the four ranges of neck movements (lateral flexion, ante- and retroflexion and rotation) were restricted to at least grade 2 (7.5 and 7.6). Neck pain was recorded in 4.8% of the 4,683 respondents in phase two. The prevalence rate of grade 2 or more cervical spondylosis in the total population was 4.9% (table 7.1). It increased with advancing age in both sexes. Men had twice as much cervical spondylosis compared to women.

In men there was a fourfold increase in the frequency of grade 2 or more cervical spondylosis in the age-group 65 years and over when compared to the age-group of 55 - 64 years. In women the frequency doubled in the same age-group. Grade 3 or more cervical spondylosis was present in 2.4% in both sexes. It pre-vailed in men in the age-group of 65 years and over but was absent in women of that particular age-group. Both neck pain and pain on movement of the neck were less common than grade 2 or

Table 7.1 Age- and sex-specific distribution of clinical cervical spondylosis and physical findings in 4,683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
C.S. grade 2^+	—	0.5	9.5	7.9	14.7	63.7	7.3
C.S. grade 3^+	—	0.6	9.8	1.5	5.9	18.9	3.3
Pain on mov.	—	2.6	6.3	6.7	5.5	19.3	7.3
Ltd antefl.2^+	—	—	7.7	5.7	10.6	45.1	5.7
Ltd rotat. 2^+	—	—	8.3	7.8	12.8	32.5	6.3
Ltd exten. 2^+	—	0.5	8.9	12.1	6.1	40.8	5.5
Ltd lat.fl.2^+	—	—	9.0	7.9	21.8	42.0	7.5
Women number	851	585	412	339	202	110	2499
C.S. grade 2^+	—	4.3	3.1	5.1	3.9	9.0	2.9
C.S. grade 3^+	—	—	4.2	2.9	4.8	—	1.5
Pain on mov.	4.5	4.2	4.6	5.3	3.4	4.8	4.5
Ltd antefl.2^+	4.6	—	1.5	1.2	2.5	1.0	1.8
Ltd rotat. 2^+	—	—	3.9	3.7	5.2	23.0	2.6
Ltd exten. 2^+	—	3.4	2.4	2.6	3.6	10.1	2.3
Ltd lat.fl.2^+	—	0.4	3.3	7.4	7.3	20.3	3.1
Men + Women	1531	1097	773	656	385	241	4683
C.S. grade 2^+	—	2.5	6.1	6.5	9.0	38.7	4.9
C.S. grade 3^+	—	0.3	6.8	2.2	5.3	10.3	2.4
Pain on mov.	2.5	3.5	5.4	6.0	4.4	12.7	5.8
Ltd antefl.2^+	2.5	—	4.4	3.4	6.4	25.0	3.5
Ltd rotat. 2^+	—	—	6.0	5.7	8.8	28.2	4.3
Ltd exten. 2^+	—	2.0	5.4	7.2	7.6	26.8	3.8
Ltd lat.fl.2^+	—	0.2	6.0	7.6	14.2	32.1	5.2

C.S. = cervical spondylosis
mov. = movement
Ltd = limited
antefl. = anteflexion
rotat. = rotation
exten. = extension
lat. = lateral
fl. = flexion

more cervical spondylosis which indicated that some of the respondents with cervical spondylosis did not have symptoms of the neck. Limitation of neck movement also increased sharply in both sexes in the age-group of 65 years and over. The sensit-

ivity, specificity and predictive value of a positive finding on physical examination for clinical cervical spondylosis are presented in table 7.2. Grade 2 or more physical findings of the neck were more than 99% specific in both sexes. The lowest sensitivity was observed for limited anteflexion. Predictive values of a positive test of grade 2 or more limitation of neck movements were as expected less than grade 3 or more physical findings except for limitation of anteflexion in women. Grade 3 or more limitation of neck movements were correspondingly less sensitive than grade 2 or more abnormalities.

Table 7.2 Sensitivity, specificity, and predictive value of a positive test of grade 2 or more and grade 3 or more abnormalities on physical examination for clinical cervical spondylosis grade 2 or more in 4,683 people fifteen years and over (in percentages)

Prevalence	Sensitivity				Specificity		Pos.pred.val.	
Grade	2+	3+	2^+	3^+	2^+	3^+	2^+	3^+
Men (n = 2184)								
Ltd antefl.	5.7	1.5	76.3	47.0	99.9	100.0	97.7	100.0
Ltd rotat.	6.3	2.5	85.1	69.6	99.0	100.0	87.4	100.0
Ltd exten.	5.5	3.2	92.1	84.7	99.4	100.0	88.2	100.0
Ltd lat.fl.	7.5	3.3	86.0	76.1	98.7	99.9	83.7	98.1
Women (n = 2499)								
Ltd antefl.	1.8	0.1	23.0	0.0	98.9	99.9	37.9	0.0
Ltd rotat.	2.6	1.1	65.6	50.0	99.8	91.2	90.0	91.2
Ltd exten.	2.3	0.6	64.0	31.2	99.6	99.9	81.2	83.2
Ltd lat.fl.	3.1	0.05	77.0	6.7	99.1	100.0	72.3	100.0
Men + Women (n = 4683)								
Ltd antefl.	3.5	0.7	47.9	21.9	99.4	100.0	65.8	46.6
Ltd rotat.	4.3	1.8	74.7	59.2	99.4	95.3	89.3	95.3
Ltd exten.	3.8	1.8	77.1	56.2	99.5	100.0	84.5	91.0
Ltd lat.fl.	5.2	1.6	81.3	39.1	89.9	100.0	77.6	99.1

See for legend table 7.1

7.3 Dorsal spondylosis

The dorsal region comprised approximately the interscapular region. Grade 2 and grade 3 or more dorsal spondylosis were found in 0.7% and 0.4% respectively, being more prevalent in men than in women. Prevalence increased with advancing age in both sexes. Because of the very low prevalence rate sensitivity, specificity and predictive value were not calculated for the findings on physical examination of the dorsal back.

7.4 Lumbar spondylosis

The low back comprised the lumbar and sacral region. The examination was done in prone, sitting and standing position and limitations were graded on a 0 - 4 point scale. In recumbency the knee, achilles and footsole reflexes were investigated.

The prevalence rate of grade 2 or more lumbar spondylosis was 4.1% (table 7.3). It was twice as common in men compared to women. In men there was a sharp increase in the age-group of 65 years and over. Limitation of retroflexion was the most sensitive and predictive sign for clinical lumbar spondylosis (table 7.4).

Grade 3 or more lumbar spondylosis was only observed in 0.8% of the people predominantly in men. Its frequency increased with advancing age. Grade 3 or more physical findings showed the same tendencies as grade 2 or more abnormalities. Their sensitivity, specificity and predictive value are not presented here.

Table 7.3 Age- and sex-specific distribution of clinical lumbar spondylosis and lumbar physical findings in 4,683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
Lumbar spond.2^+	—	0.6	8.6	1.6	9.4	50.9	5.5
Lumbar spond.3^+	—	—	0.9	0.9	—	21.0	1.5
Ltd rotat. 2^+	—	8.4	0.6	10.0	15.1	18.9	5.9
Ltd antefl.2^+	—	8.4	2.1	9.4	15.2	21.2	6.9
Ltd retrofl.2^+	—	7.4	1.0	3.6	6.5	20.1	4.2
Back pain mov.	0.8	18.5	46.2	38.0	26.9	23.8	16.1
Women number	851	585	412	339	202	110	2499
Lumbar spond.2^+	—	4.2	5.7	2.8	4.5	7.2	2.9
Lumbar spond.3^+	—	—	0.3	—	1.2	1.6	0.1
Ltd rotat. 2^+	0.5	4.9	12.3	12.1	9.6	24.0	6.8
Ltd antefl. 2^+	—	4.6	5.0	4.1	0.6	4.8	3.6
Ltd retrofl.2^+	—	—	6.0	2.5	4.8	7.7	2.1
Back pain mov.	9.8	21.5	25.8	20.9	19.6	16.5	17.8
Men + Women	1531	1097	773	656	385	241	4683
Lumbar spond.2^+	—	3.3	7.6	2.5	7.1	28.4	4.1
Lumbar spond.3^+	—	—	0.7	0.4	1.3	11.9	0.8
Ltd rotat. 2^+	0.3	6.5	7.0	11.0	12.3	21.1	6.4
Ltd antefl. 2^+	—	6.3	4.1	6.6	6.8	12.9	5.2
Ltd retrofl.2^+	—	3.4	3.7	3.0	5.7	14.3	3.1
Back pain mov.	6.5	20.6	30.7	28.3	22.8	20.0	19.5

See for legend table 7.1

Table 7.4 Sensitivity, specificity, and predictive value of a positive test of grade 2 or more abnormalities on physical examination for clinical dorsal-lumbar spondylosis grade 2 or more in 4683 people fifteen years and over
(in percentages)

Grade	Sensitivity 2^+	Specificity 2^+	Pos.pred.val. 2^+
Men (n = 2184)			
Ltd rotation	9.1	95.1	7.6
Ltd anteflexion	42.0	97.6	47.4
Ltd retroflexion	54.5	98.8	72.7
Women (n = 2499)			
Ltd rotation	28.9	95.3	15.1
Ltd anteflexion	57.3	97.7	36.9
Ltd retroflexion	44.1	99.1	59.3
Men + Women (n = 4683)			
Ltd rotation	17.7	95.2	11.7
Ltd anteflexion	46.9	97.5	42.6
Ltd retroflexion	50.7	99.0	67.8

7.5 Lumbago, sciatica and disc prolapse

Lumbago

Paralumbar myalgia was diagnosed as lumbago and comprised mostly of tenderness and limited range of movements of the low back due to pain (7.7 and 7.8). Overall lumbago was present in 20% of the people and was more frequently seen in men than in women (table 7.5). Lumbago occurred in all age-groups and increased to prevalence rates of 30 to 50% in the age-group of 65 years and over. Tender spots of the back and back pain on movement showed relatively low sensitivities, specificities and

Table 7.5 Age- and sex-specific distribution of lumbago and tender spot in 4,683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
Lumbago	3.9	18.0	34.7	22.8	34.4	55.3	22.7
Back tender spot	0.9	19.4	37.7	36.6	32.5	27.3	20.7
Women number	851	585	412	339	202	110	2499
Lumbago	18.0	17.8	18.3	17.9	22.0	32.5	18.4
Back tender spot	10.9	22.6	19.8	26.5	25.3	17.5	18.7
Men + Women	1531	1097	773	656	385	241	4683
Lumbago	4.4	30.0	27.4	20.3	32.3	44.9	20.4
Back tender spot	7.0	21.4	27.4	31.0	28.5	22.1	19.6

Table 7.6 Sensitivity, specificity and predictive value of back pain parameters for grade 2 and more lumbar spondylosis in 4,683 people fifteen years and over (in percentages)

	Sensitivity	Specificity	Pos.pred.val.
Men (n = 2184)			
Back pain on movement	40.3	79.6	9.3
Back tender spot	39.0	80.2	9.2
Women (n = 2499)			
Back pain on movement	74.1	83.8	11.5
Back tender spot	57.6	82.4	8.7
Men + Women (n = 4683)			
Back pain on movement	53.6	81.9	10.4
Back tender spot	46.4	81.4	8.9

predictive values for the diagnosis of lumbar spondylosis (table 7.6) indicating that the examining physician did not consider

them to be related to degenerative spinal disease. Tender spots occurred as frequently as lumbago.

Disc prolapse

Disc prolapse was considered to be present when the respondent had a history of shooting back pain irradiating into one or both legs down to the calf or foot, impaired straight leg raising (SLR) and/or reflex abnormalities of the knee and/or ankle jerks (7.9-7.13).

Disc prolapse was found in 2.3% of the population (table 7.7). It was predominantly located on the right side of the back and was more frequently found in men than in women similar as in the Western world (7.6 and 7.14). Disc prolapse occurred in all agegroups in this sample population. It was more or less uniformly distributed over the age-groups and somewhat more frequent after the age of 65 years in both sexes. Impaired straight leg raising had a low sensitivity but high positive predictive value for disc prolapse (table 7.8), indicating that only 60% of the people considered to have disc prolapse showed impaired SLR and therefore the diagnosis either was based on a typical history or on reflex abnormalities.

Sciatica

Sciatica was present when symptoms and signs of irritation of the sciatic nerve and/or tenderness (pressure points along the course of the nerve with an impaired straight leg raising test) existed (7.12). Sciatica was found in 3.0% and was more prevalent in the men than in the women. Sciatica had a very high sensitivity and specificity for the clinical diagnosis of disc prolapse (7.8) suggesting that the examining physician considered the presence of sciatica to be highly associated with a herniated disc be it with a moderate predictive value for that condition.

Kyphosis and lordosis

Grade 2 or more kyphosis and lordosis were only observed after 35 years of age. They were both slightly more frequent in women. The prevalence rates were low, 2.0% for kyphosis and 0.7% for increased lordosis. Because of the low prevalence rates no further analysis was done.

Table 7.7 Age- and sex-specific distribution of disc prolapse, sciatica and impaired straight leg raising in 4,683 people fifteen years and over in (percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
Disc prolapse	—	0.4	4.8	3.4	4.4	6.2	3.8
Sciatica	—	8.1	5.5	6.0	4.5	8.0	4.5
SLR impaired	—	6.5	0.5	3.4	1.6	6.7	2.6
Women number	851	585	412	339	202	110	2499
Disc prolapse	0.2	3.2	—	1.7	—	1.4	1.0
Sciatica	—	3.6	—	1.9	—	9.8	1.6
SLR impaired	0.3	—	—	2.4	0.8	2.4	0.7
Men + women	1531	1097	773	656	385	241	4683
Disc prolapse	0.1	2.4	2.0	2.7	1.9	3.9	2.3
Sciatica	—	5.8	2.4	3.9	2.0	10.0	2.9
SLR impaired	0.1	3.3	0.3	2.6	1.3	4.7	1.6

Table 7.8 Sensitivity, specificity, and predictive value of sciatic and impaired straight leg raising for disc prolapse in 4,683 people fifteen years and over (in percentages)

	Sensitivity	Specificity	Pos.pred.val.
Men (n = 2184)			
Sciatica	100.0	99.1	80.5
Straight leg raising	62.7	99.7	90.2
Women (n = 2499)			
Sciatica	91.2	99.4	63.6
Straight leg raising	47.8	99.9	78.4
Men + Women (n = 4683)			
Sciatica	97.8	99.3	75.8
Straight leg raising	59.0	99.8	87.5

7.6 Discussion

Ankylosing spondylitis was not observed among the 946 respondents of phase four, but in seven clinical sacro-iliitis was suspected, but not seen on the pelvic film.

Population samples examined by the Arthritis and Rheumatism Council in the UK found lumbar disc prolapse to occur in 4.8% in the men and 2.5% in the women fifteen years and over (7.6), while in the Indonesian survey only 3.8% of the men and 1.0% of the women of the sample population suffered from this condition (table 7.7). Interobserver variation and different protocols used could have contributed to the differences in the prevalence rates of disc prolapse in different populations (7.17) surveyed (table 7.9).

Table 7.9 Grade 2 or more disc prolapse in population samples (in percentages)

Population sample	Age-group	Examined	Percentages
Indonesia	35-64	1814	1.8
Rhondda, UK	35-64	526	1.3
Zoetermeer, Holland	35-64	3782	1.9
Leigh, UK	35-64	927	2.3
Jamaica	35-64	535	3.0
Watford, UK	35-64	204	3.9
Wensleydale, UK	35-64	482	8.5

UK = United Kingdom

In the age-group of 35 - 64 years Indonesians had the lowest prevalence rate except for Rhondda, U.K., and the same as in the Netherlands. The various other areas in England had higher rates for disc prolapse as had Jamaica, another developing country.

Clinical cervical spondylosis occurred in about one quarter of the Zoetermeer population in Holland (7.16). Even after age-standardization the rates were more than four times higher than in the Indonesian population. Except for pain on movement of the neck, the rates for limitation of rotation, ante-and retroflexion

ere correspondingly higher in the Dutch population. It is rather attractive to speculate that the reason for this difference is a better use of the cervical spine and its musculature in daily life, as the rural Indonesian people and particularly the women tend to carry loads on their head. On examination they showed a better developed cervical, dorsal and lumbar musculature than the Caucasian respondents, as one of the observers (H.A. Valkenburg) who participated in both surveys can endorse.

Sensitivity, specificity and predictive value of physical neck parameters were not calculated for the Zoetermeer study and could therefore not be compared.

The diagnosis clinical lumbar spondylosis was not made in the EPOZ study as the analysis was based on radiological disc degeneration. However, after age-standardization limitation of the various back movements occurred two to three times as often in comparison with the Indonesian study (7.14). Contrary to this finding lumbago occurred four times more frequently in the Indonesian people (20% as opposed to 5%). As there was a very high association between tender spots in the low back region and the diagnosis lumbago in the Indonesian survey, this possibly could explain the differences between the two populations. A better developed lumbar musculature and a better mobility of the low back might be the reason for the five times lower prevalence rates of kyphosis and increased lordosis as compared to the Dutch study, but overloading of the back could have caused tenderness of the back musculature and lumbago.

The prevalence rate of sciatica was 1.9% for the men and 2.2% for the women in the EPOZ study and therefore comparable to the rates in Indonesia.

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CHAPTER VIII

OSTEO-ARTHRITIS OF PERIPHERAL JOINTS

8.1 Introduction

Clinical judgment of degenerative joint disease was based on a typical history of pain in the joints at rest, on movement and on pressure - particularly so on weight bearing -, stiffness after immobility and loosening up after a few movement and signs of bony swelling, joint crepitus and limitations of movements without evidence of systemic disease (8.1 and 8.2). Degenerative joint disease with clinical symptoms was assigned the term osteo-arthritis and for the radiological signs of degenerative joint disease the term osteo-arthrosis was applied throughout the thesis. Localized OA (LOA) was considered to be present when less than 3 joints were affected; generalized OA (GOA) when 3 or more joints were involved.

8.2 Osteo-arthritis (OA)

Clinical osteo-arthritis (COA) was diagnosed based on the examination of thirty peripheral joint(group)s excluding the spine.

The prevalence rate of grade 2 or more clinical osteo-arthritis was 5.1% (table 8.1), which most likely was a gross underestimation.

The rates increased with advancing age and particularly so in the 65 years and over age-group. COA was more prevalent in the women than in the men with a male to female ratio of 1:1.6 (table 8.1). Grade 2 or more LOA was found in 3.7%. It was more prevalent in the women than in the men as was GOA grade 2 or more. GOA grade 3 or more was diagnosed in 0.3%. GOA appeared only after 45 years of age. Women were more frequently affected than men with a male to female ratio of 1:5.5.

Table 8.1 Age- and sex-specific distribution of grade 2 or more clinical localized osteo-arthritis (LOA) and generalized osteo-arthritis (GOA) in 4,683 people fifteen years and over (in percentages)

Agegroups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
LOA	---	0.4	4.2	3.7	8.8	18.9	3.4
GOA	---	---	---	0.5	1.6	7.0	0.5
Total OA	---	0.4	4.2	4.2	10.4	25.9	3.9
Women number	851	585	412	339	202	110	2499
LOA	0.2	6.9	4.3	6.3	2.7	11.2	3.8
GOA	---	---	---	4.4	12.0	18.1	2.4
Total OA	0.2	6.9	4.3	10.7	14.7	29.3	6.2
Men + Women	1531	1097	773	656	385	241	4683
LOA	0.1	4.4	4.7	5.3	5.0	14.1	3.7
GOA	---	---	---	2.2	7.3	13.2	1.5
Total OA	0.1	4.4	4.7	7.5	12.3	27.3	5.1

LOA = localized osteo-arthritis
GOA = generalized osteo-arthritis
OA = osteo-arthritis

8.3 Heberden's nodes

Heberden's nodes and bony enlargement of the distal interphalangeal (DIP) joints were recorded for the right and left side separately (8.3). It was impossible to differentiate between traumatic and idiopathic forms of Heberden's nodes. Almost all the people were engaged in manual labour and trauma to the DIP joints was common, whether relevant or not as to the induction or worsening of the condition (8.4).

Heberden's nodes and DIP bony enlargement were predominantly encountered on the right side. DIP bony enlargement was found in 1.6% of the men and in 2.8% of the women with a male to

Table 8.2 Age- and sex-specific distribution of Heberden's nodes and distal interphalangeal bony enlargement in 4,683 people thirty-five years and over (in percentages)

Age-groups	35–44	45–54	55–64	65+	45+	15+
Men number	361	317	183	131	631	2184
Heberden right	—	3.2	1.3	12.4	5.5	1.6
Heberden left	—	0.7	—	—	0.2	0.06
Heberden bilateral	—	0.7	2.5	4.4	1.1	0.3
Heberden any site	—	4.5	3.8	16.8	6.8	2.0
DIPbe right	—	2.4	2.9	5.0	3.8	1.1
DIPbe left	—	0.5	—	—	0.2	0.06
DIPbe bilateral	—	0.5	1.9	6.6	1.6	0.5
DIPbe any site	—	3.4	4.8	11.6	5.5	1.6
Women number	412	339	202	110	651	2499
Heberden right	—	2.0	10.6	26.1	8.6	2.2
Heberden left	—	—	—	—	—	—
Heberden bilateral	0.5	2.0	11.6	2.5	5.5	1.4
Hbn any site	0.5	3.9	22.2	28.6	14.1	3.7
DIPbe right	0.5	4.1	7.6	—	5.3	1.4
DIPbe left	—	—	—	—	—	—
DIPbe bilateral	—	2.4	7.6	14.2	5.5	1.4
DIPbe any site	0.5	6.5	15.2	14.2	10.8	2.8
Men + Women	773	656	385	241	1282	4683
Heberden right	—	2.7	6.4	19.7	6.1	1.6
Heberden left	—	0.4	—	—	0.1	0.03
Heberden bilateral	0.3	1.4	5.8	3.7	4.5	1.2
Hbn any site	0.3	4.4	12.3	23.4	10.7	2.9
DIPbe right	0.2	3.3	5.3	3.1	4.5	1.2
DIPbe left	—	0.3	—	—	0.1	0.03
DIPbe bilateral	—	1.4	4.7	10.2	3.6	1.0
DIPbe any site	0.2	5.0	10.0	13.3	8.3	2.3

Hbn = Heberden
DIPbe = distal interphalangeal bony enlargement

female ratio of 1:1.4. Heberden's nodes were noticed in 3.7% of the women and in 2.0% of the men with a male to female ratio of 1:1.9 (table 8.2). Both Heberden's nodes and DIP bony enlargement were only seen after 35 years of age and tended to increase in frequency with advancing age.

The association between noted bony enlargement of the DIP joints and Heberden's nodes was reasonable but far from perfect (kappa for males 0.71; for females 0.68).

8.4 Radiological osteo-arthrosis (ROA)

In the hands radiological osteo-arthrosis was most frequently observed in the DIP joints (21% in both sexes), followed by the MCP (8.4%), the wrist (4.7%), the PIP (4.4%), CMC-I (3.8%) and the carpal joints (1.5%). The MCP joints and the wrists were 1.5 to 3 times more often affected in the men; the PIP joints four times more often in the women.

The remaining rates for radiological OA of the hand joints were about the same in men and women (table 8.3). In the feet the MTP-I joint was most often affected (17% in the men and 15% in the women), while OA of the other feet joints was rare and at about equal rates in both sexes (table 8.4).

Radiological OA started mainly after 35 years to reach sometimes values of over 50% in the age-groups 65 years and over (for the DIP joints 51.0-61.1% ; for the MTP-I joints 48.7-65.1%). ROA of the wrist joints was irregularly distributed over the age-groups, suggesting a more secondary nature of this condition.

The sex ratio fluctuated around 1.0 with notable exceptions for the PIP joints and the wrists. After age-standardization the male to female ratio's approached those observed in the EPOZ study with exception of the PIP, CMC-I, carpal and wrist joints of the hands and the PIP joints of the feet (table 8.5).

Table 8.3 Age- and sex-specific distribution of radiological OA grade 2 or more of the hands in 4683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
DIP	—	2.4	2.9	23.1	30.5	51.0	21.1
PIP	—	—	—	1.5	4.3	15.9	1.5
MCP	—	—	2.9	5.0	18.3	22.5	10.2
CMC-I	—	—	0.7	6.6	22.3	14.7	3.8
CMC-L	—	—	—	—	—	—	—
Carpal	—	—	—	7.9	1.4	7.4	1.7
Wrist	—	0.6	19.2	12.2	7.9	29.9	7.5
Women number	851	585	412	339	202	110	2499
DIP	2.2	3.6	13.2	30.8	41.4	61.1	20.9
PIP	—	—	2.6	8.2	10.8	27.8	6.9
MCP	—	1.2	0.9	11.0	10.8	16.7	6.9
CMC-I	—	1.2	3.4	8.2	16.4	11.7	3.8
CMC-L	—	—	0.7	0.8	4.3	—	0.6
Carpal	—	—	4.2	1.1	3.7	2.2	1.2
Wrist	—	0.4	7.5	4.0	4.7	2.2	2.3
Men + Women	1531	1097	773	656	385	241	4683
DIP	1.7	3.2	9.3	27.3	36.8	55.3	21.0
PIP	—	—	1.6	5.6	8.3	20.0	4.4
MCP	—	0.8	1.6	8.2	14.0	20.8	8.4
CMC-I	—	0.6	2.1	7.4	19.2	13.3	3.8
CMC-L	—	—	0.4	0.4	2.2	—	0.3
Carpal	—	—	2.2	4.4	2.1	5.0	1.5
Wrist	—	0.5	13.0	8.0	6.2	17.1	4.7

DIP = distal interphalangeal joints
PIP = proximal interphalangeal joints
MCP = metacarpophalangeal joints
CMC = carpometacarpal joints
I = first
L = lateral

Table 8.4 Age- and sex-specific distribution of radiological OA grade 2 or more of the feet in 4,683 people fifteen years and over (in percentages)

Agegroups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
PIP	—	—	—	2.2	4.2	7.0	1.1
MTP-I	—	—	26.8	29.2	53.3	65.1	17.0
MTP-L	—	—	1.6	6.5	9.6	6.9	2.4
TMT	—	—	3.6	5.2	6.3	8.8	2.4
Women number	851	585	412	339	202	110	2499
PIP	—	—	—	2.7	6.1	13.1	1.4
MTP-I	9.5	10.0	12.8	18.0	34.2	48.7	15.0
MTP-L	—	—	1.7	4.0	5.2	16.1	2.0
TMT	—	—	2.0	7.8	8.5	12.6	2.6
Men + Women	1531	1097	773	656	385	241	4683
PIP	—	—	—	2.5	5.2	9.7	1.3
MTP-I	5.3	5.3	19.3	23.4	43.3	57.6	15.9
MTP-L	—	—	1.7	5.2	7.3	11.1	2.2
TMT	—	—	2.7	6.5	7.5	10.5	2.5

MTP = metatarsophalangeal joints I = first
TMT = tarsometatarsal joints L = lateral

Table 8.5 Sex ratio of grade 2 or more radiological OA of the hand and foot joints in 4,683 people fifteen years and over (before and after age-standardization to the EPOZ-study)

Country	Indonesia before standardization	EPOZ	Indonesia after standardization
	Ratio women to men		
Hands			
PIP	4.6	2.0	3.2
CMC-I	1.1	2.0	1.1
DIP	1.0	1.5	1.6
MCP	0.7	1.3	1.6
Carpal	0.7	1.6	0.7
Wrist	0.3	0.8	0.3
Feet			
Foot PIP	1.3	0.9	1.9
MTP-I	0.9	1.2	0.8
MTP-L	0.8	1.4	1.1
TMT	0.8	1.0	1.3

8.5 Discussion

As already stated the observed prevalence rates of localized osteo-arthritis (LOA) and generalized osteo-arthritis (GOA) most likely are underestimates. In part this was caused by interobserver variation between the three principal clinical examiners, the author, K.D. Muirden, and H.A. Valkenburg, but mainly it was due to the fact that during the physical examinations non-rheumatological colleagues of the local medical school participated in the study. They were found to overlook the diagnosis of mild clinical osteo-arthritis. As approximately 25% of the respondents were seen by these voluntarily participating co lleagues, the observed prevalence rate of peripheral clinical

osteo-arthritis can only be compared cautiously with other surveys (8.5 and 8.6) as some of the examiners overlooked or misinterpreted the condition.

In the EPOZ study combined LOA and GOA was found in 26% of the men and 35% of the women. The observed rate of 5% in the Indonesian survey must be incorrect. On the other hand it is unlikely that correction for the observer bias could raise the frequency to the levels observed in most other studies (8.7-8.9).

Clinical osteo-arthritis of the hip was not encountered in the 912 people fifteen years and over examined in phase four. Radiological grade 2 OA of the hips was seen, however, in two out of seven pelvic films which were made for suspected sacro-iliitis.

Osteo-arthritis of the knee could not be evaluated as crepitus and bony enlargement of this joint by omission were not examined in phase four. On request fifty-six people (6.1%) got p.a.-films of the knees on weight bearing and twenty five (45%) of those showed grade 2 or more radiological osteo-arthrosis. Most of the X-rays of the knees were made because of joint fluid observed on physical examination. The minimal prevalence rate of clinical knee OA can thus be calculated to be 15.5% in the men and 12.7% in the women, while the minimal rates of radiological knee OA in this population sample of fifteen years and older would be 4.2% and 7.8% respectively. Just these figures alone deny already the above-mentioned low estimates of LOA in the Indonesian population.

The prevalence rate of clinical osteo-arthritis in the Javanese was 3.4 times the rate when compared to the Inuit Indians (table 8.6) in Canada (8.10), though the sex ratio was almost similar for the two population samples (not age-standardized).

The UK an Dutch surveys (8.7 and 8.24) also observed Heberden's nodes 1.9 times more often in women than in men. Heberden's nodes show quite marked population differences. In Nigeria and Liberia Muller only found a prevalence rate of 1.6% in 831 adults examined (8.11). In New Zealand Wigley found a prevalence rate of 4.6% in the migrant Tokelauans and 11.3% in the non-migrant Tokelauans in the Tokelau Islands of fifteen years and over (8.12 and 8.13). In the age-groups of 35 - 64 years, Indonesia

had the lowest prevalence rate of Heberden's nodes (not age-standardized) followed by the Netherlands (8.24), Jamaica (8.14) and Wensleydale (table 8.7).

Table 8.6 Sex-specific distribution of clinical osteo-arthritis in different populations fifteen years and over (in percentages)

Country	Race	Number	Men	Women	Men + Women	M:F Ratio
Indonesia	Javanese	4,683	3.9	6.2	5.1	1:1.6
Canada	Inuit	2,055	1.2	2.1	1.5	1:1.8

Table 8.7 Heberden's nodes in different populations (in percentages)

Country	Number of people examined	Heb.nodes grade 2 or more
Nigeria and Liberia#	831	1.6
New Zealand, migrant#	1381	4.6
non-migrant#	811	11.3
Indonesia#	4683	2.9
Indonesia*	1814	4.3
The Netherlands	3463	5.5
Jamaica*	533	9.9
Wensleydale* (UK)	482	13.9

15+ years

* in the age-group 35 - 64 years.

In the Indonesian and the Dutch study the same observer was involved in the X-ray analysis of hands and feet. As furthermore the EPOZ study up to now has been the largest in which radiographs of hands and feet were obtained, the age-standardized prevalence rates of radiological OA of the hands and feet joints are presented in table 8.8.

Table 8.8 To the EPOZ-study age-standardized prevalence rates of grade 2 or more radiological osteo-arthrosis in 1,504 men and 1,648 women 25 years and over (in percentages)

HAND JOINTS			FEET JOINTS		
Joint	EPOZ	Indonesia	Joint	EPOZ	Indonesia
Men					
DIP	18.4	16.5	PIP	4.9	1.8
PIP	5.3	2.6	MTP-I	22.1	28.7
MCP	15.5	4.3	MTP-L	3.7	4.1
CMC-I	7.7	6.5	TMT	3.4	4.1
CMC-L	0.3	---			
Carpal	4.2	2.9			
Wrist	6.0	12.6			
Women					
DIP	28.0	25.8	PIP	4.6	3.4
PIP	10.8	8.2	MTP-I	27.4	21.6
MCP	19.8	6.9	MTP-L	5.2	4.5
CMC-I	15.1	6.9	TMT	3.6	5.2
CMC-L	0.7	0.9			
Carpal	6.6	2.1			
Wrist	4.8	3.9			
Men + Women					
DIP	23.5	21.6	PIP	4.7	2.5
PIP	8.2	5.4	MTP-I	24.7	25.1
MCP	17.6	7.0	MTP-L	4.5	4.1
CMC-I	11.7	6.7	TMT	3.5	4.6
CMC-L	0.5	0.5			
Carpal	5.5	2.5			
Wrist	5.4	8.5			

See tables 8.3 and 8.4 for legend

The rates are about the same for the DIP, CMC-I, CMC-lateral, carpal, MTP-I, MTP-lateral, and TMT-joints in men, and for the DIP, PIP, CMC-lateral, wrist, PIP-feet, MTP-I, MTP-lateral, and TMT-joints in women. The most obvious differences occurred for the MCP-joints in both sexes, where the Dutch rates are three times higher; for the wrist in men (Indonesia twice higher), the carpal joints in women (three times higher in the EPOZ study) and the PIP joints of the feet in men (EPOZ higher). No ready explanation is available for the differences in MCP, carpal and PIP-feet ROA. The difference in wrist ROA could be due to secondary (traumatic?) OA. The fact that the rates for osteo-arthrosis were the same for MTP-I in both populations suggest that wearing shoes has no bearing on degenerative changes in that joint.

Grade 3 radiological OA was rare in the Indonesian people. For those joints where reasonable estimates were available in the Indonesian survey, age-specific rates for grade 3 or more ROA were two to eight times lower as compared to the U.K. (8.15) and EPOZ.

The most important determinant of radiological OA is age. From the available literature the age-relation is not affected by sex, race or geography (8.16-8.18).

In the relatively undernourished population of Bandungan, overweight was unlikely to be an important factor where clinical and radiological OA was concerned.

Almost twice as many men as women carried loads of 20 or more kg daily. Very heavy load carrying occurred in equal percentages in both sexes (about 6%). Half the population walked more than 5 km daily (table 1.2).

Occupation was very weakly associated with rheumatic disorders in the EPOZ study (8.19). Occupation does not seem to be related to radiological osteo-arthrosis and clinical osteo-arthritis (8.20). In this population sample more than 75% of the people were involved in heavy manual labour but this apparently did not influence the rates of radiological osteo-arthrosis.

For several decades the feet of these male mountaineers, balancing 30 - 60 kg of weight by means of a resilient wooden pole on their shoulders, and the females carrying lighter loads on their back by means of a cotton band strapped diagonally over

their shoulders, walking up and down hill over rough terrain covering a distance of several kilometers daily and at least several times weekly, underwent tremendous physical strain and stress. Yet the prevalence rates of radiological osteo-arthrosis of the feet was low and did not differ from the people in Zoetermeer (table 8.8). Apparently healthy joints are structured to withstand repetitive daily minor trauma. Given the time to adapt, even severe physical strain such as carrying loads of fifty kg down or uphill over a distance of several kilometers is tolerated well by the feet without noticeable untowards effects. One wonders whether walking barefooted is not an advantage over the shoe wearing habit of developed populations. Long-distance running is associated with an increase of bone mineral content but not with radiological and clinical osteo-arthritis of the axial and peripheral joints (8.20 and 8.21) in particular weight-bearing joints.

An exception in this Indonesian population might be the knee joints. Based on the minimal estimate of some 14% clinical osteo-arthritis and at least 6% radiological OA in people fifteen years and over, one might speculate that the knees of these life-long squatting mountaineers are overburdened, which together with regular knee trauma might induce a higher rate of knee OA than in developed populations. Further study would be necessary to substantiate this. As the majority of people with radiological osteo-arthrosis of the hands and feet have no symptoms (8.22 and 8.23) and physical signs have a poor predictive value where radiological abnormalities are concerned (8.24) such a study would necessitate the evaluation of both clinical signs and symptoms and X-ray assessment in people living under different physical strain of their knees.

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CHAPTER IX
EXTRA-ARTICULAR RHEUMATISM

9.1 Introduction

In this study an attempt was made to obtain an estimate of extra-articular rheumatic conditions (also called soft tissue rheumatism) in the Bandungan population. One of the two conditions - lumbago and tender spots of the back region - have already been described in chapter VII. In this chapter shoulder fibrositis and epicondylitis will be presented.

9.2 Shoulder fibrositis

By "shoulder" was meant the shoulder joint, its periarticular structures and the trapezius muscle. Pain on active and passive movement of the arm and tenderness of the proximal part of the biceps tendons were entered in the examination sheets. Restriction of frontal elevation, abduction, endo- and exorotation were scored according to a five points scale (chapter III 3.3). Based on clinical judgement the diagnosis of shoulder fibrositis was established.

Shoulder fibrositis was diagnosed in 14.5% of the 4683 people fifteen years and over (table 9.1). There was a more or less equal frequency over the age-groups from 25 years onward. It occurred predominantly on the right side, but bilateral involvement was found in 5%. It was slightly more frequent in women (14.9%) than in men (13.9%).

Tender spots of the shoulder region were the most prevalent findings observed in 29.0% of the men and in 35.5% of the women (table 9.2). Tender spots apparently led to the diagnosis shoulder fibrositis (table 9.3) as judged from the very high sensitivity and specificity of this sign. Restriction of the various shoulder movements had a very low sensitivity for shoulder fibrositis in the women with a correspondingly low predictive value for this condition. In men these figures were definitely better though not very convincing as to their contribution in establishing the diagnosis.

Table 9.1 Age-, sex- and location-specific distribution of shoulder fibrositis in 4,683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
Left only	0.4	7.2	5.2	4.6	7.5	14.2	5.3
Right only	—	14.7	11.4	1.9	4.0	5.6	5.1
Bilateral	—	1.0	5.2	5.4	5.7	10.5	3.5
Total	0.4	22.2	21.8	11.9	17.2	30.3	13.9
Women number	851	585	412	339	202	110	2499
Left only	—	1.9	1.3	1.5	1.2	1.5	0.9
Right only	5.4	8.7	12.5	7.1	8.2	15.2	7.5
Bilateral	4.9	4.9	4.9	9.6	10.7	4.3	6.5
Total	10.3	15.5	18.7	18.2	20.1	21.0	14.9
Men + Women	1531	1097	773	656	385	241	4683
Left only	0.2	4.1	2.9	2.8	3.9	7.7	3.0
Right only	3.2	10.9	12.0	4.7	6.3	10.2	6.4
Bilateral	2.9	3.2	5.0	7.7	8.5	7.1	5.1
Total	6.2	18.2	20.0	15.3	18.8	25.3	14.5

All physical parameters were highly specific for the diagnosis.

Table 9.2 Location-specific distribution of shoulderpain, tender spots and limitation of movement in 4,683 people fifteen years and over (in percentages)

Physical finding	Left	Right	Bilateral	Total
Men (n = 2184)				
Pain on movement	2.9	5.6	0.6	9.1
Tender spots	11.2	12.2	5.6	29.0
Pain in shoulder girdle	2.9	5.0	0.8	8.7
Limitation of elevation	2.8	1.7	1.0	5.5
Limitation of abduction	1.6	1.5	1.4	4.5
Limitation of rotation	2.5	1.8	0.9	5.2
Women (n = 2499)				
Pain on movement	2.1	3.9	10.1	16.1
Tender spots	9.7	17.1	8.7	35.5
Pain in shoulder girdle	1.5	4.5	1.1	7.1
Limitation of elevation	0.8	0.8	0.7	2.3
Limitation of abduction	0.2	0.4	0.1	0.7
Limitation of rotation	0.2	0.3	0.1	0.6
Men + Women (n = 4683)				
Pain on movement	2.5	4.7	5.7	12.9
Tender spots	10.4	14.8	7.3	32.5
Pain in shoulder girdle	2.2	4.6	1.0	7.8
Limitation of elevation	1.7	1.2	0.8	3.7
Limitation of abduction	0.8	0.9	0.7	2.4
Limitation of rotation	1.3	1.0	0.5	2.8

Table 9.3 Sensitivity, specificity, and predictive value of left and right shoulder signs and symptoms for the corresponding diagnosis of shoulder fibrositis in 4,683 people fifteen years and over

(in percentages)

	Sensitivity		Specificity		Predict.value	
	Left	Right	Left	Right	Left	Right
Men (n = 2184)						
Pain on movement	28.3	46.7	99.5	98.3	84.7	71.6
Tender spot	83.4	99.3	95.7	96.0	65.4	70.2
Pain in girdle	29.0	48.2	99.6	99.0	86.9	82.3
Limited elevation	31.2	11.9	99.9	99.2	95.5	59.3
Limited abduction	17.4	9.6	99.9	98.5	96.0	37.2
Limited rotation	40.8	11.9	99.9	98.4	97.6	41.1
Women (n = 2499)						
Pain on movement	26.5	31.0	99.8	99.1	93.2	84.3
Tender spot	92.3	87.4	96.9	92.9	70.1	66.8
Pain in girdle	20.1	25.9	99.9	99.3	96.9	85.4
Limited elevation	2.6	5.5	99.4	99.5	25.1	61.6
Limited abduction	1.7	2.4	99.9	99.9	72.7	77.8
Limited rotation	2.6	2.1	99.9	99.9	80.0	85.7
Men + Women (n = 4683)						
Pain on movement	27.4	36.5	99.7	98.7	88.5	78.1
Tender spot	87.4	91.6	96.3	94.4	67.7	68.1
Pain in girdle	24.6	33.7	99.8	99.2	90.6	83.8
Limited elevation	17.2	7.7	99.2	99.3	79.1	60.4
Limited abduction	9.7	4.9	99.9	99.2	93.4	44.5
Limited rotation	16.0	5.5	99.9	99.2	95.9	47.1

9.3 Epicondylitis

As with shoulder fibrositis the clinical diagnosis of epicondylitis was left to the interpretation of the examiner. Pain on movement and on pressure of the lateral and medial condyle were entered on the data sheet.

Among the 4,683 people surveyed, epicondylitis was diagnosed in 5.6%. It ranked third in the prevalence of rheumatic diseases seen. Bilateral epicondylitis was most prevalent in both sexes. Rightsided epicondylitis occurred more often than leftsided. Epicondylitis was somewhat more prevalent in women than in men (table 9.4).

Table 9.4 Age-, sex- and location-specific distribution of epicondylitis in 4,683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
Left only	—	0.5	1.4	1.9	2.4	—	0.5
Right only	—	—	7.1	0.7	4.2	2.0	1.7
Bilateral	—	0.5	1.9	4.9	9.7	8.3	2.9
Total	—	1.2	10.2	7.5	16.5	10.3	5.0
Women number	851	585	412	339	202	110	2499
Left only	0.3	0.7	0.9	1.1	—	—	0.6
Right only	0.5	1.0	3.6	7.0	4.2	2.1	2.4
Bilateral	—	0.3	5.4	12.4	6.1	—	3.2
Total	0.8	2.1	9.9	20.6	10.4	2.1	6.1
Men + women	1531	1097	773	656	385	241	4683
Left only	0.2	0.6	1.1	1.5	1.1	—	0.6
Right only	0.3	0.5	5.2	4.0	4.2	2.0	2.1
Bilateral	—	0.4	3.8	8.8	7.8	4.5	3.1
Total	0.4	1.7	10.0	14.3	13.3	6.6	5.6

Elbow pain of the lateral condyles was more frequently encountered than elbow pain of the medial condyles. Elbow pain on movement was rare (table 9.5).

Elbow pain on movement was not sensitive (9.0%) for the diagnosis of epicondylitis, but had a high specificity and a 55% predictive value (table 9.6). Pain on pressure of the lateral condyles was highly associated with the diagnosis epicondylitis with a sensitivity of 93.1%, specificity of 97.8% an a predictive value of 69.5%.

Table 9.5 Location specific distribution of elbow pain on movement, and pressure on the medial and lateral condyle in 4,683 people fifteen years and over (in percentages)

Physical findings	Right	Left	Bilateral	Total
Men (n = 2184)				
Pain on movement	0.1	0.1	0.1	0.3
Tenderness of the medial condyle	2.4	0.4	2.1	2.9
Tenderness of the lateral condyle	3.8	0.5	2.3	6.6
Women (n = 2499)				
Pain on movement	1.1	0.1	0.4	1.6
Tenderness of the medial condyle	1.9	0.3	2.6	4.8
Tenderness of the lateral condyle	2.7	0.9	3.7	7.3
Men + Women (n = 4683)				
Pain on movement	0.6	0.1	0.1	0.8
Tenderness of the medial condyle	2.2	0.4	2.4	5.0
Tenderness of the lateral condyle	3.2	0.7	3.0	6.9

Table 9.6 Sensitivity, specificity and predictive value of elbow parameters for the diagnosis of epicondylitis (in percentages)

	Sensitivity	Specificity	Predictive value of a positive test
Men (n = 2184)			
Elbow pain on movement	2.8	99.9	50.0
Elbow pain medial condyle	49.3	97.1	44.9
Elbow pain lateral condyle	83.1	79.0	56.7
Women (n + 2499)			
Elbow pain on movement	13.2	99.3	55.2
Elbow pain medial condyle	58.4	98.5	70.7
Elbow pain lateral condyle	100.0	98.4	79.6
Men + Women (n + 4683)			
Elbow pain on movement	9.0	99.6	54.5
Elbow pain medial condyle	54.7	97.9	58.4
Elbow pain lateral condyle	93.1	97.8	69.5

9.4 Discussion

No comparable epidemiological data are available in the literature. In the EPOZ-study two different diagnostic categories were applied for shoulder conditions: muscular spasm of the trapezoid, not comparable to the tender spots registered in Bandungan and periarticualr fibrositis. Together they occurred in 20% of the women and 13% of the men. As tender spots were highly associated with fibrositis (table 9.3), the prevalence rates for fibrositis in Bandungan are likely comparable with the combined rates for the shoulder conditions in Zoetermeer. Epidcondylitis occurred in 2% of the men and in 4% of the women in the EPOZ-study, distinctly less than in the Indonesian study.

CHAPTER X
GOUT

10.1 Prevalence of gout

Based on clinical judgement/New York criteria (appendices 12, 13, 14) the prevalence rate of gout was 0.8% in the 4,683 people 15 years and older (table 10.1). The overall male to female ratio was thirty-four to one. Gout occurred in 1.7% of the men and 0.05% of the women. It was predominantly found in men 45 years and over. Acute gouty arthritis and chronic tophaceous gout were both found in this population sample.

Table 10.1 Age- and sex-specific distribution of gout in 4,683 people fifteen years and over
(in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
Prevalence rate	0.6	---	---	7.9	2.8	2.4	1.7
Women number	851	585	412	339	202	110	2499
Prevalence rate	---	---	---	---	---	1.1	0.05
Men + Women	1531	1097	773	656	385	241	4683
Prevalence rate	0.3	---	---	3.6	1.3	2.5	0.8

Case presentation of chronic tophaceous gout

One man was suffering from gout for over thirty years when first seen in 1982 during the phase two interview survey. He was a classical case of chronic tophaceous gout with a typical history from the very beginning (10.1). In 1952 at the age of thirty-nine years, the patient went sound and healthy to bed and woke up between 1 - 2 a.m. by an excruciating pain in the right knee accompanied by a chill and fever. He could not sleep for the rest of the night. The next morning the right knee was ex-

tremely sensitive and painful, swollen, stiff, warm and red. He could not stand and walk for several days. Eventually he recovered within a week without treatment or sequelae. Four years later in 1956, a similar attack occurred in the left knee, which also cleared up without any aftermath within one week. Since 1957 he had once a year an acute attack of red, swollen, painful, stiff, warm and tender joints until 1960. The first annual attack was in the left 1st MTP joint followed by the right 1st MTP joint, thereupon alternating between the 1st MTP joints while the duration of time before resolution of the arthritis increased to over two weeks. After 1960 the attacks of acute arthritis occurred several times each year, but in between the attacks the patient was healthy and his physical activities were not restricted. He noticed his first tophus in 1970 and thereafter was tortured every month by an acute bout of arthritis preceded by fever and a chill, sometimes accompanied by shivering. Surprisingly there was no history of shedding of urinary stones. When first seen in July 1983 the patient was able to walk with a stick. When physically examined in January 1986 he had deteriorated into functional class four and moving outside the house was only possible by carrying him piggyback.

Due to bone resorption his big and second toes became shorter (figs. 10.1 and 10.2). Even his heels and hands were covered with tophi (figs. 10.3, 10.4, 10.5). After suffering thirty years from gout, his X-ray film of the feet showed progressive destruction and bone resorption (10.2, 10.6) during a period of two and a half years lasting from July 1983 (fig. 10.2) to January 1986 (fig. 10.6). Bone resorption and joint destruc-tion in the hands were not as severe as in the feet (fig. 10.5). Earscrappings of tiny nodules proved to contain birefringent monosodium urate crystals under polarized light (10.4). Laboratory procedures were normal for liver and kidney function, and blood count. The ESR was 47 mm/1 hour Westergren, and the uric acid level 8 mg/100 ml. The mean urinary urate excretion per twenty-four hours was normal (550 mg).

Fig. 10.1

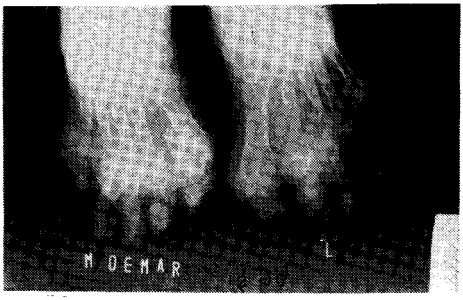


Fig. 10.2

Fig. 10.3

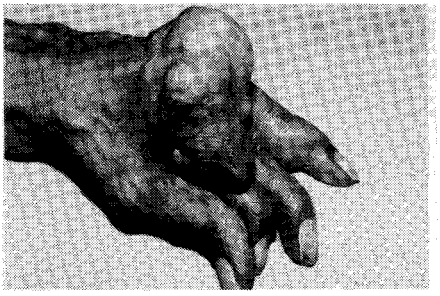


Fig. 10.4

Fig. 10.5

Fig. 10.6

Fig. 10 Tophaceous gout in Bandungan

10.2 Relation between initial complaints and serum uric acid level.

Above a concentration of about 0.42 mmol/litre (7 mg/100 ml), plasma is saturated with urate. The upper limit or cut off point for hyperuricaemia is set pragmatically at 0.42 mmol/litre (7 mg/100 ml) for men and 0.36 mmol/litre (6 mg/100 ml) for women according to the Council for the International Organization of Medical Sciences for use in the diagnosis of gout in epidemiological studies (10.5).

Of the 27 people (14 men and 13 women) in the phase two study, who said to have had an acute attack of pain in the big toe with or without swelling or redness and which attack did or did not subside in two weeks time, 24 (12 men and 12 women) were seen in phase four. Five of the men (42%) and 4 of the women (33%) had hyperuricaemia. The three men in phase two who had acute pain and swelling and redness and where the attack went over within two weeks all were hyperuricaemic and one got the clinical diagnosis of gout in phase four (see case presentation). The one woman in phase two who had a similar history also was hyperuricaemic.

Eight cases of gout (7 men and one woman) were diagnosed in the phase four study. Four of the seven men or 57% were hyperuricaemic, the one woman was not. However, the examining physicians were unaware of the findings of the phase two study and had to base their diagnosis on the situation as it presented itself during the phase four study, particularly where signs and symptoms were concerned. Apparently they did not select any better on the presence of hyperuricaemia than the simple questions on gout in phase two did.

10.3 Prevalence of hyperuricaemia

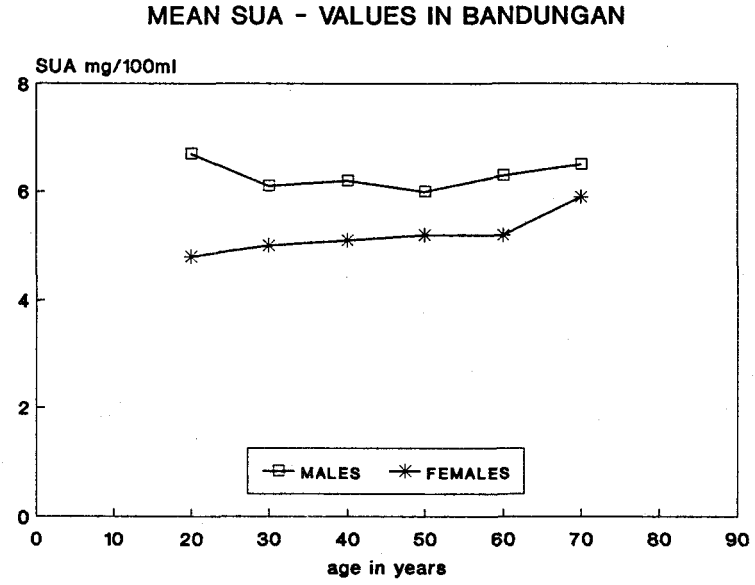
For both sexes the weighted mean of the serum uric acid (SUA) levels tested by the enzymatic method was 5.4 mg/100 ml with a standard deviation of 1.08 mg/100ml (table 10.2). In general cases and controls had the same mean SUA values and were therefore combined. The highest mean SUA value in men was observed in the age group 15 - 24 years (6.7 mg/100ml) followed by

the oldest age group. The other mean SUA values in men were rather constant over the total age range.

Table 10.2 Status-, age- and sex-specific distribution of mean serum uric acid levels and its standard deviations (in mg/100ml)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Weighted mean
Control men (n)	5	12	22	35	22	10	106
Mean	6.8	6.3	6.3	5.8	6.3	6.7	6.2
Standard deviation	0.65	1.56	1.40	1.21	1.32	1.15	1.28
Cases men (n)	8	23	44	74	55	33	237
Mean	6.7	6.0	6.1	6.1	6.3	6.4	6.2
Standard deviation	1.64	0.89	1.05	1.14	1.48	1.43	1.24
Total men mean	6.7	6.1	6.2	6.0	6.3	6.5	6.2
S.D.	1.26	1.12	1.17	1.16	1.43	1.36	1.25
Control women (n)	20	27	38	42	28	7	162
Mean	4.9	5.0	5.1	5.5	5.4	6.3	5.3
Standard deviation	0.50	0.88	0.94	1.25	1.10	1.77	1.02
Cases women (n)	23	52	69	91	77	26	338
Mean	4.8	5.0	5.1	5.1	5.1	5.8	5.1
Standard deviation	0.82	0.75	1.15	1.20	0.90	1.30	1.03
Total women mean	4.8	5.0	5.1	5.2	5.2	5.9	5.2
S.D.	0.67	0.79	1.08	1.22	0.67	1.40	0.90
Total men+women mean	5.2	5.3	5.5	5.6	5.7	6.2	5.4
S.D. men+women	0.81	0.89	1.11	1.19	1.19	1.38	1.08

In women mean SUA values increased from 4.8 mg/100 ml in the age group 15 - 24 years to 5.0 mg/100 ml in the next, to stay constant until the oldest group where it increased to 5.9 mg/100 ml. In men and women combined a steady increase in mean SUA values was observed (fig. 10.7).
For comparison the values for the EPOZ study are also presented.



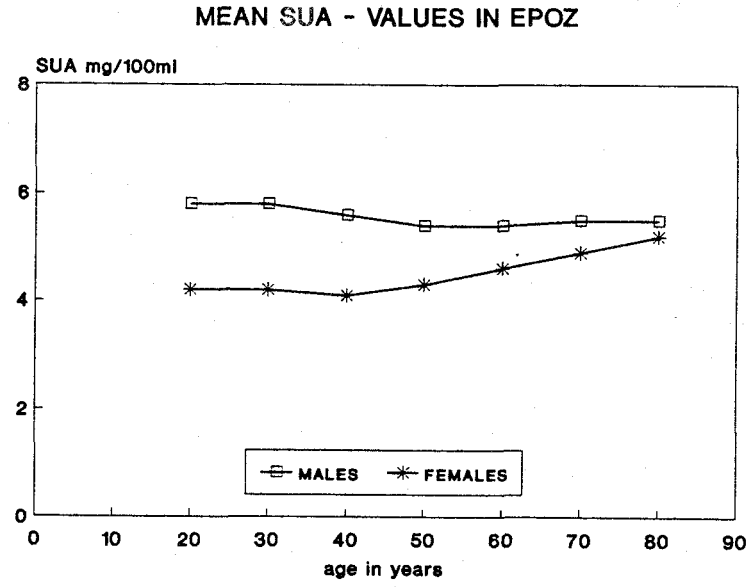


Fig. 10.7 Age- and sex-specific mean SUA values in Bandungan and EPOZ population

At the cut off point of >7.0 mg/100ml 24.3% of the men were hyperuricaemic and at a cut off point of >6.0 mg/100ml 11.7% of the women (table 10.3). For both sexes this figure was 17.6%.

Table 10.3 Age- and sex-specific distribution of hyperuricemia in 4,683 people fifteen years and over (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	680	512	361	317	183	131	2184
> 7 mg/100ml	33.6	10.9	23.3	18.8	26.1	41.7	24.3
Women number	851	585	412	339	202	110	2499
> 6 mg/100ml	4.7	8.6	13.3	20.9	22.6	27.8	11.7
Men + Women	1531	1097	773	656	385	241	4683
Hyperuricaemic	17.5	4.6	17.9	19.9	24.3	35.4	17.6

Among the men 2.9% of the serum samples showed a SUA level of more than 9.0 mg/100 ml. Only 30% of those exceeding this value had gout. Among the women 0.8% of the serum samples showed values of more than 9.0 mg/100 ml. None had gout. The prevalence rate of hyperuricaemia increased progressively with advancing age in both sexes except in the age group 15 - 24 years in men where it obtained the second highest value. The lowest level of SUA was 2.8 mg/100 ml. Defining hypo-uricaemia as a SUA level of < 2 mg/100 ml no cases of hypouricaemia were encountered in this population sample (10.6 and 10.7).

10.4 Discussion

The prevalence rate of gout of seventeen cases per one thousand men and five cases per ten thousand women or eight cases per thousand people for both sexes for Indonesia is rather high when compared to other population surveys. Lawrence in his book (10.8) describes that in Caucasians similar figures were observed in New Zealand (10.9), Watford, UK (10.10) and New Haven, USA (10.11). In other Caucasian populations in the UK (10.12 and 10.13), the USA (10.14 and 10.15), Finland (10.16), the Netherlands (10.17) and Bulgaria (10.18) the rates are less than three per thousand men and with the exception of Leigh, UK (10.12) the disease is not observed in women. In Amerindians (10.19), African Negroes (10.10 and 10.20) and Japanese (10.21) the disease is absent in men and women or the rates in men stay below four per thousand.

Very high rates are observed among the migrant Maoris (10.9) and the Pukapukans of the Cook Islands (10.9) - 93 and 60 per thousand men respectively - while rates between 25 and 40 per thousand men are found in Alaskan Filipinos (10.15) and on the Mariana Islands (10.22). While the migrant Maoris in New Zealand were found to have the highest rates for gout, the non-migrant Maoris still living in the Tokolau Islands had a lower prevalence rate of gout than Indonesia (10.23 - 10.25).

When only those cases with gout who showed concomittantly hyperuricaemia in phase four are taken into account the male prevalence rate for clinical gout of nine per thousand is still higher than in most populations studied sofar and reflects the high prevalence rate for hyperuricaemia in this population.

Although the SUA levels from different populations can not directly be compared because of methodological differences between the enzymatic and the colorimetric method, defining the cut off point of hyperuricaemia for the enzymatic method at > 6 mg/100 ml and the colorimetric methods at > 6.5 mg/100 ml, would allow for such a comparison and this was done in table 10.4 for the various male prevalence rates in other population surveys. As gout prevails in men relatively few female populations have been studied and those data are not presented here.

Table 10.4 Hyperuricaemia in different male adult populations

Country	Ethnic group	Number tested	SUA mean SD	Percentage hyperur.
Mariana Islands	Carolinians (10.22)	26	7.3 ± 1.7	62
New Zealand	Polynesians (10.9)	796	7.0 ± 1.3	59
Hawaii	Filipinos (10.26)	60	6.3 ± 1.3	45
Alaska	Filipinos (10.26)	119	6.3 ± 1.4	41
Philippines	Filipinos (10.27)	223	6.3 ± 1.2	-
Malaysia	Malays(10.27)	169	6.3 ± 1.2	-
Hawaii	Filipinos (10.28)	236	6.2 -	-
Mariana Islands	Chamorros (10.19)	160	6.2 ± 1.5	53
Indonesia	Javanese	343	6.2 ± 1.3	43
New Zealand	Caucasians (10.9)	202	6.2 ± 1.2	38
Malaysia	Chinese (10.27)	298	6.1 ± 1.3	-
Malaysia	Tamils (10.27)	197	6.1 ± 1.2	-
Netherlands	Caucasians (10.44)	2925	5.6 ± 1.1	30
Canada	Chinese (10.29)	100	5.4 ± 1.1	30
North America	Caucasians (10.14)	7,471	5.4 ± 1.2	13
Montana, USA	Blackfeet (10.19)	587	5.2 ± 1.1	21
Tecumseh, USA	Caucasians (10.30)	1,379	5.2 ± 1.3	20
Finland	Caucasians (10.16)	737	5.0 ± 1.1	5
Taiwan	Chinese (10.27)	208	5.0 ± 0.8	-
UK	Caucasians (10.10)	452	4.8 ± 1.1	5
Jamaica	Negros (10.10)	260	4.8 ± 1.1	13
Liberia/Nigeria	Negros (10.20)	151	4.5 ± 0.9	8
Japan	Japanese (10.18/10.31)	378	4.5 ± 1.1	9
Arizona, USA	Pimas (10.19)	473	4.6 ± 1.2	10
Canada	Haidas (10.29)	237	4.4 ± 1.0	5

The mean SUA level of 6.2 mg/100 ml in the Indonesian sample ranks nine and is lower than the values found in the Carolinians of the Mariana Islands and Polynesians in New Zealand and the Cook Islands (10.9). The mean SUA level of the Javanese males is of the same magnitude as of the Filipinos, Malays, Tamils and Chinese in Malaysia and the Caucasians in New Zealand. The mean SUA values of the Caucasians in North America, the UK,

the Netherlands and Finland are between 4.8 and 5.6 mg/100 ml. The Amerindians, West African Negroes and Japanese have the lowest SUA levels.

Neel (10.32) studied a small group of male Xavante Indians of the Brazilian Mato Groso and found them to have mean SUA levels of the magnitude of the Polynesians in New Zealand. He explains differences between ethnic groups and within one ethnic group living under different circumstances by the interaction of genotype and environment. For four ethnic groups, the Filipinos, Maoris, Chinese and American Indians, there is evidence for both 'hyperuricaemic' and 'normo-uricaemic' subpopulations. Acculturation might lead to higher SUA levels (Filipinos and Maoris) or lower (some Amerindians). For the Chinese it looks like as if acculturation to the western life style has decreased mean SUA levels, but no figures are available from mainland China. On the other hand all three ethnic groups (Malays, Tamils and Chinese) in Malaysia show high mean SUA levels suggesting the influence of environmental factors, as might be the case with the New Zealand Caucasian population which is largely from European (UK) descent.

In the Indonesian population sample the age-specific distribution of mean SUA values follows the same pattern as in the Tecumseh population study (10.30) and in the EPOZ-population be it at higher levels, explaining why gout in premenopausal women is virtually absent and mainly occurs after the age of fifty, while in men gout might develop from 20 years onwards.

The prevalence of hyperuricaemia roughly follows the population mean SUA levels. Unfortunately these figures are not given for the populations studied by Duff et al (10.27). Large variations in percentages hyperuricaemia are observed for the Caucasian populations studied, particularly so in comparing the US population with West-European populations. Negroes of West-African descent have low mean SUA levels and relatively low prevalence rates of hyperuricaemia as have Amerindians with the exception of the Blackfeet Indians from Montana.

In the Indonesian population the percentage hyperuricaemia in men also reflects the mean SUA level. About 7% of those with hyperuricaemia above 6.0 mg/100 ml had gout, a figure close to the 10% found in Tecumseh (10.30).

The nutritional pattern of the Bandungan inhabitants does not provide clues for the elevated mean SUA levels. Based on national figures (10.33) rural people consumed 2500 calories daily, 66% of which was provided by cereals. Per capita daily consumption of protein was 53 g. Of this only 11% was animal protein, while cereals provided 63% of the daily protein intake. Per capita fat consumption was 48 g, of which 80% was derived from oily seeds, peanuts, coconuts and palm oil.

In an overall Muslim population the consumption of alcohol is nil or negligible. The only major source of nucleoprotein intake came from the frequently but not daily consumption of yeast fermented bean cake (*tempe*). Still the prevalence rate of gout was high as compared to some Caucasian populations who consume considerable amounts of alcohol and meat daily.

The Tokolauan males living in New Zealand had a high meat and alcohol consumption and showed a prevalence rate of gout of 40 per thousand (10.34). Those still living mainly on fish on the Pacific Atolls had a prevalence rate of 20 per thousand (10.35). Whereas the people in Bandungan with a very low meat, poultry and fish consumption had a prevalence rate of 17 per thousand males. However, when the disease becomes chronic and tophaceous it can be as severe as anywhere in the world (case presentation). But obviously the risk factor for the development of hyperuricaemia and gout in this population sample is not the excessive use of meat and/or fish or alcohol. On the contrary, hyperuricaemia could rather be the result of under-nourishment (10.36 and 10.37).

SUA levels tend to be lower among the poor than among the prosperous (10.13, 10.38 and 10.39) and it is higher in people who are physically bulky than in those who are slim (10.22, 10.40-10.42). Acheson (10.11) could show a positive association between social class and the prevalence of gout, but not between social class and SUA levels (10.43). As 93% of the Bandungan people were farmers or farm-hands social class can not be a determinant of SUA and gout in this population. Neither can be obesity. The mean Quetelet index of the males was 20.3 ± 0.13 and of the females 21.8 ± 0.19 and overweight among the men according to European standards was non-existent.

The likelihood therefore is that both hyperuricaemia and

gout in this Indonesian population are genetically determined, although a hitherto unknown environmental factor in e.g. the food can not be excluded.

Gout is an example of a rheumatic condition where secondary prevention is appropriate. The aim of secondary prevention is to reduce the deveopment of manifest disease by early treatment. By detecting the disease at a preclinical stage the loss of joint function and handicap can be minimized. Handicap has been defined by the WHO (1980) as:

> "disadvantage for a given individual resulting from impairment or a disability that limits or prevents fulfilment of a role that is normal depending on age, sex, and social and cultural factors for that individual".

Gout is a disease which can be diagnosed at an early stage because of its typical history and the availability of an accurate diagnostic test. The treatment of gout can be entirely successful as effective urate lowering medication is available and chronic tophaceous gout as described earlier in this chapter can then be prevented.

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CHAPTER XI
MISCELLANEOUS CONDITIONS

11.1 Systemic Lupus Erythematosus

During the checking of the phase two questionnaires a woman of twenty-three years was seen by the author who suffered from arthritis, oral ulcers, photosensitivity and a malar rash (butterfly rash) on her face. Raynaud's phenomenon was ascertained after a lengthy questioning. Her phase two questionnaire was marked with S.L.E. She was again seen after twenty months during the phase three examination in October 1984 and was in a better condition because of the Rheumacyl (5 mg of prednison, 200 mg of phenylbutazon, 300 mg of paracetamol and buffered by antacids) she was taking whenever the family could afford it. Arthralgia, oral ulcers, photosensitivity, and a trace of butterfly rash were still present. As she fulfilled four criteria of the A.R.A. 1982 Revised Criteria (11.1) for the classification of systemic lupus erythematosus (appendix 15), she was considered to be a definite case. She was not seen during the January 1986 epidemiological survey for reasons that like the definite rheumatoid cases she belonged to the seventy deaths registered by the PHWs.

In an environment with inadequate primary health care not upgraded to the level of the skill required for the management of systemic lupus erythematosus and its complications and a population living at a minimal subsistence level (11.2), undoubtedly the mortality of this disease is very high particularly so where infectious diseases are the number one cause of morbidity and mortality (11.3) in the area. Based on the per capita annual income and expenditure for the rural Indonesian population in 1984, it could be calculated that barely US$ 35.- per year was left for miscellaneous goods and services, such as health care. This small amount was certainly inadequate for maintenance treatment of systemic lupus erythematosus, not to mention a lupus crisis or complications of the disease.

In the author's less than two decades clinical experience with the care of patients with systemic lupus erythematosus, the five years survival rate is zero for the destitutes, where the supply of medicines and in particular corticosteroids is irreg-

ular or sporadic and only as financial resources permit and no family or social support is available for the occasional intensive treatment necessary for the complications of SLE. Ten years survival rate is common in patients who can afford and obtain adequate medical care for their disease and its complications. By multivariate analysis Stephanie Studenski has shown that race and socio-economic status exert an independent negative effect on the survival of patients with systemic lupus erythematosus (11.4).

Community based studies in the United States (11.5, 11.6), U.K. (11.7), Sweden (11.8), and a nationwide database in Finland (11.9) found the prevalence rates of systemic lupus erythematosus to range from 6.0 to 50.8 cases per 100.000 persons. The prevalence of systemic lupus erythematosus of 4 per 10,000 women in the Bandungan population is for obvious reasons a far from realistic estimate, but it illustrates that the condition exists. Hochberg estimated the prevalence rate of systemic lupus erythematosus in England and Wales to be 17.7 cases per 100,000 women of 15 - 64 years (11.7). Due to a higher mortality rate than in rheumatoid arthritis, systemic lupus erythematosus cases are less frequently seen than would be expected in Indonesia (at least in the experience of the author).

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11.2 Reiter's syndrome

During the phase two study two cases were seen whom fulfilled the criteria for classical Reiter's syndrome (11.10, 11.11), one man and one woman (11.12). This was on clinical impression without laboratory support. Both cases had chronic conjunctivitis, but not endemic trachoma, asymmmetrical lower extremity arthritis and a history of several bouts of urethritis. ALthough both were seen again in phase four, they were in remission because of corticosteroid and phenylbutazon treatment. In epidemiological surveys Reiter's syndrome commonly is underdiagnosed as the syndrome has no ascertaining diagnostic test, venereal disease history may be suppressed, enteric features very easily are forgotten, and stomatitis, balanitis, and urethritis may be asymptomatic in both sexes while chronic conjunctivitis is common in the Bandungan area. Reiter's syndrome is multifactoral in its cause and has a varied manifestation (11.13). Definite

Reiter's syndrome without the classical triad should have been more frequently encountered in this Indonesian population where enteric infections are endemic and venereal diseases not uncommon.

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11.3 Past polyarthritis

Grade 2 or more past polyarthritis was not found in the men fifteen years and over seen in phase four. Its prevalence in women was 0.2%. This low prevalence could be due to the already observed high mortality among rheumatoid patients during the active stages of the disease, not leaving any burned-out patients in the population.

11.4 Fibrous nodules of the shoulder girdles

This paragraph describes single or multiple subcutaneous nodules in seven males. They were observed during the phase four study among 946 people fifteen years and over, five among the 178 male cases with rheumatic complaints and two in the 125 male controls (fig. 11.1A-D). The prevalence rate in males is therefore 2%. None were observed among females. The frequency in males makes nodules a relatively common condition and even this may be an underestimation as smaller nodules may have been over-

looked in the mass screening procedures as none of the seven reported pain in the shoulders and the subjects attributed these lumps to carrying heavy loads balanced on a pole on the shoulders.

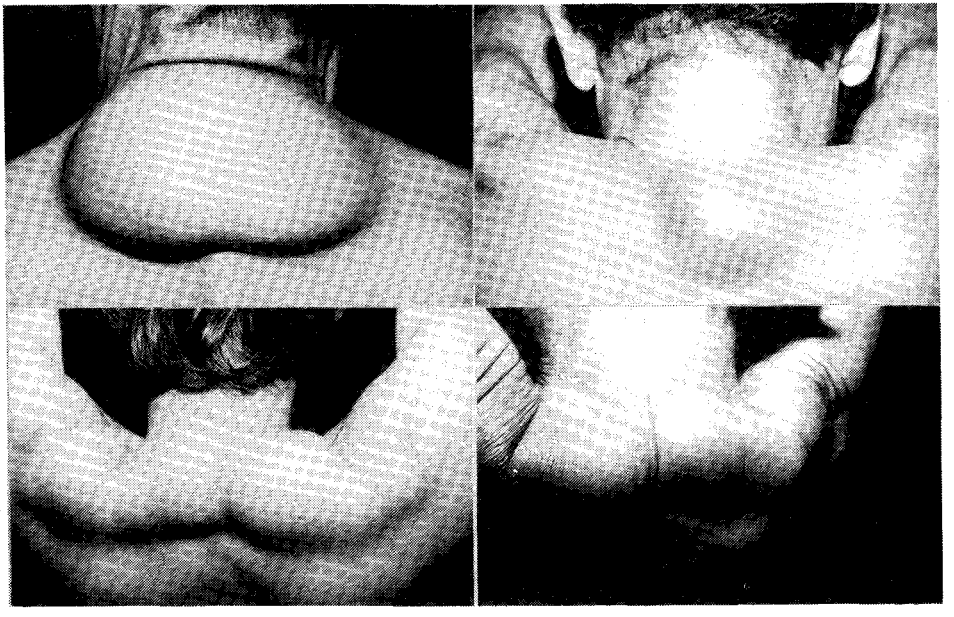


Fig. 11.1 Single, triple, quintuplet and quadruplet shoulder nodules of varying size, shape and consistency in a sixty-eight (A), fifty-eight (B), thirty-three (C) and forty-two (D) years old male.

Women also transport agricultural products or wood for fire on their back but by means of a cotton band strapped diagonally over the shoulder (fig. 11.2). The loads are generally less heavy than those carried by the men.

The shoulder nodules became obvious two to six years after the start of physical or mechanical irritation. Males may commence carrying loads in this traditional way as early as twelve years of age or as late as forty eight. All load carriers had an initial history of abraded skin, which sometimes bled and soreness of both shoulders for one to several weeks. The average weight carried was sixty to seventy kilograms and the daily distance walked was ten to twenty kilometers.

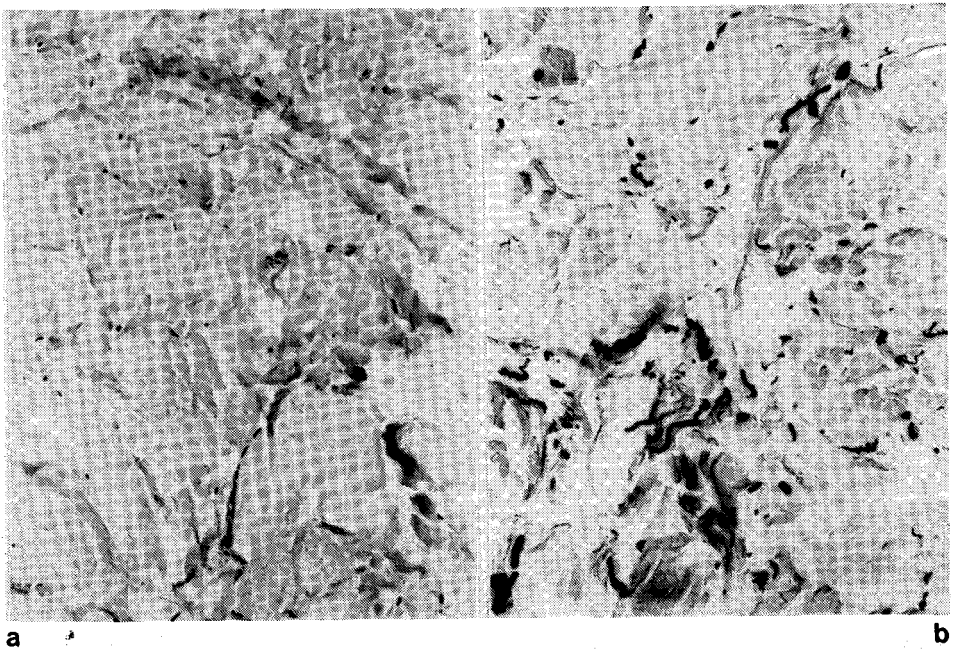
Fig.11.2 A man balances a rather heavy load for his size by means of a resilient wooden pole on his shoulder. A woman carries a load on her back by means of a cotton band slanted across her shoulder.

The shoulder mass was tough and hard on palpation and needling if the chronic mechanical irritation was continuing or soft when this activity had been stopped some years before.

The shoulder lumps varied from 1x2x3 to 5x10x15 cms in size and did not restrict movements of the neck, shoulders, arms or back. They were usually not tender and there were no inflammatory changes in the overlying skin. The masses became more prominent on abduction of the arms (fig.1C,D). Regardless of the number of lumps, the central tumor over the spinous process of the seventh cervical vertebra was a constant feature in the seven cases examined. All subjects denied diminishing carrying capacity, but stated that the central nodule did hinder the shifting of the pole from one shoulder to another, a procedure necessary to relieve pressure on one side after walking several hundred meters. The initial impression that these lumps were bursae

filled with fluid caused by chronic mechanical friction was refuted by aspiration attempts and soft tissue X-ray, which showed only an ill-defined soft tissue density without cavitation or calcification. Chest and scapular X-rays, neurological examination and clinical laboratory procedures were normal. No other shoulder abnormality, neoplasm, or connective tissue disease was detected.

Biopsy of the nodules showed connective tissue with low cell density and abundant and strikingly coarse bundles of collagen fibers among which some elastin fibers were scattered. These elastin fibers were coarse and slightly irregular in outline but not markedly degenerate. No elastin globules were present. There was no inflammatory infiltrate. The picture showed vague resemblance to elastofibroma, but the amount of elastin fibers was too small and their contour too smooth for this diagnosis (fig.11.3).



a b

Fig.11.3 A biopsy showing connective tissue with low cell density and abundant coarse bundles of collagen fibers, among which some elastin fibers are scattered. A: haematoxylin and eosin, x 160; B: elastin van Gieson stain, x 200.

Among the seven patients with these fibrous nodules, there were a father and son aged respectively fifty-six and thirty-six years. Further inquiries revealed that the late grandfather had had a shoulder nodule as well, which was further corroborated by neighbours. The son had two adult brothers and three sisters and the father four brothers and three sisters and evidently none of these were affected, despite the fact that the male kin also carried loads on their shoulders in a similar fashion. No family history was available on the grandfather. The father started carrying loads at the age of twelve and his shoulder lumps appeared at eighteen. His son began carrying loads at the age of thirteen and his shoulder nodule also became visible at eighteen. Both had a single central lump over the area of the spinous process of the seventh cervical vertebra. The history indicated that the late grandfather also had one central nodule. There was no family history of similar shoulder nodules in the other five respondents. Another case occurred in one of the two primary health care workers who carried out the initial interview survey. He commenced balancing loads by means of a pole at the age of forty-eight and his shoulder nodule appeared when he was aged fifty-two years.

In another Indonesian survey among 418 urban residents no shoulder nodules were observed in either sex. A thorough history revealed that none of the men who were engaged in manual labour had ever balanced loads by means of a pole on his shoulders.

Discussion

Similar shoulder nodules have been observed in seven men by K.D. Muirden and R.D. Wigley together with Dr. Lourdes Manahan in one Philippine village in a similar population survey covering 482 men the majority of whom were engaged in farming and also used poles to carry loads. Unfortunately no biopsies were taken.

The Kikuyu bursa is a different but possibly related kind of swelling in the lumbar and sacral area occurring in adult women of the Kikuyu tribe in Kenya, Africa. These people carry loads on their back by means of a headband with the load constantly pressing on the same part of the lower back (11.14, 11.15). These swellings can be painful and either single or double with a diameter of 3 - 10 cm. In contrast to the presently

reported nodules these swellings appeared to be cystic with well-defined compartments containing gelatinous material with homogeneous appearance. Only residual fragmented elastin fibers were visible on staining.

The fibrous nodules described in this report have some features in common with elastofibroma which was first reported in 1959 by Jarvi and Saxen (11.16). Subsequent authors described the condition as a slowly growing, non-encapsulated tumor which was always benign, and which did not recur after surgical removal. Most were located in the subscapular region (11.16-11.18), but a variety of locations was observed. Their usually obscure location and mostly silent, complaint-free course is probably the reason for the low incidence reported in the literature. The age range for elastofibroma reported was seventeen to ninety-four years and the female to male ratio varied from three to one to thirteen to one in Nagamine's series (11.19). A positive family history has been noted and a relationship to local chronic mechanical irritation and inflammatory stimuli was suggested as the probable cause in possibly constitutionally predisposed persons (11.16, 11.19). The histological appearance of elastofibroma is pathognomonic.

The seven cases presented here in addition to a non-typical morphologic picture, differ from the reported elastofibroma cases in the number of swellings per location, the absence in women and location on the shoulders, a position not mentioned in the elastofibroma literature. It is therefore very likely that our observation concerns a separate entity possibly in familially predisposed males. Men with rheumatic complaints did not have a higher risk of developing these nodules and none of the cases reported pain in the region. In a stoical population which is inclined to accept pain, suffering and death as part of their fate, a few aches and pains produced by the daily pounding of a heavy wooden pole on the soft tissue of the shoulders was likely to be ignored as load carrying on the shoulders was a vital means of transport for the village economy.

The main risk factor in our series appeared to be chronic physical stress caused by the resilient wooden pole, loaded at both ends with weights of 25 - 30 kg and carried for years over many kilometers. The soft tissue of the area became abraded and

painful in the early stage. This would be followed by a massive reactive increase in the number and size of collagen fibers. One may speculate about a fibrosing reaction to repetitive mechanical or ischemic (compression induced) destruction of subcutaneous fat tissue. That fibroma-like nodules were not found in women nor in male Indonesian urban residents who do not carry poles, is consistent with the suggested causation of these nodules.

References

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11.5 Other radiological findings

11.5.1 Osteoporosis

During the reading of the hands and feet films, osteoporosis of the second metacarpals and second metatarsals was subjectively assessed and graded on a five point scale in which grade 2 to 4 stood for mild but definite to severe radiological osteoporosis. In a separate sub-study this subjective grading correlated significantly with the measured Relative Cortical Area (RCA) of six metacarpals (mean value of 100X $(D^2-d^2)/D^2$, where D represents the outer diameter and d the medullar diameter of a metacarpal bone - 11.20 and 11.21). As the same observer assessed the films of the EPOZ and the Indonesian survey, the results could be compared.

As there is no reason to believe that the case-control status of the respondents of phase four would have influenced the results on osteoporosis, the rates were directly calculated from the observed findings and not by means of the conversion factor (table 4.5).

The results for the Indonesian and Dutch surveys are presented in tables 11.1 and 11.2. It is obvious that osteoporosis is a far more prevalent condition in Indonesia than in Holland.

It occurs already at young age, particularly so in women, who at child bearing age show osteoporosis grade 2 or more of the hands in 14.7% against 0.8% in the corresponding Dutch women. Grade 2 or more osteoporosis of the feet was present in 4.9% of the Indonesian women aged 15 - 44 years, but occurred only in 0.4% of the Zoetermeer women. Osteoporosis therefore was found 12 to 18 times as often in relatively young Indonesian women when compared to Dutch women. Indonesian men of corresponding age showed 3 to 4 times more osteoporosis of the hands or feet than their Dutch counterparts. This suggests that in fertile Indonesian women an additional factor is operative in the induction of osteoporosis. Starting at the age of 45 years the process accelerates in both sexes and populations to reach values of 20% in men and more than 80% in women for the metacarpals and somewhat lesser values for the metatarsals.

Table 11.1 Age- and sex-specific distribution of radiological osteoporosis of the hands and feet in 375 men and 537 women in Bandungan fifteen years and over seen in phase four (in percentages)

Age-groups	15-24	25-34	35-44	45-54	55-64	65+	Total
Men number	13	41	69	121	82	49	375
Hands 2^+	7.7	4.9	2.9	8.3	22.0	18.6	11.2
Hands 3^+	----	2.4	---	3.3	4.9	2.0	2.7
Feet 2^+	----	---	1.5	4.1	7.3	18.4	5.8
Feet 3^+	----	---	---	---	---	6.1	0.8
Women number	46	84	114	146	111	36	537
Hands 2^+	13.0	8.3	20.2	35.6	60.4	86.1	34.6
Hands 3^+	2.2	1.2	5.3	10.3	26.1	44.4	12.7
Feet 2^+	---	3.6	7.9	21.9	36.9	63.7	19.7
Feet 3^+	---	---	0.9	7.5	13.5	36.1	7.5
Men + Women	59	125	183	267	193	85	912
Hands 2^+	11.9	7.2	13.7	23.2	44.0	47.1	25.0
Hands 3^+	1.7	1.6	3.3	7.1	17.1	20.0	8.6
Feet 2^+	---	2.4	5.5	13.9	24.4	37.7	13.2
Feet 3^+	---	---	0.6	4.1	7.8	18.8	4.7

Table 11.2 Age- and sex-specific distribution of radiological osteoporosis of the hands and feet in 2,725 men and 3,087 women in Zoetermeer twenty years and over (in percentages)

Age-groups	20-24	25-34	35-44	45-54	55-64	65+	Total
Men number	154	446	715	679	425	306	2725
Hands 2^+	---	0.7	1.8	3.7	9.9	21.6	5.5
Hands 3^+	---	0.2	0.1	0.4	1.6	4.2	0.9
Feet 2^+	---	0.5	0.1	0.7	2.1	4.5	1.1
Feet 3^+	---	0.2	---	0.3	0.5	---	0.2
Women number	152	503	801	679	450	502	3087
Hands 2^+	1.3	0.4	0.9	5.9	28.0	59.2	15.4
Hands 3^+	---	---	---	0.7	7.3	31.5	6.3
Feet 2^+	1.3	0.4	0.2	1.6	10.9	31.3	7.2
Feet 3^+	---	---	---	0.1	1.6	8.4	1.6
Men + Women	306	949	1516	1358	875	808	5812
Hands 2^+	0.6	0.5	1.3	4.8	19.2	44.9	10.7
Hands 3^+	---	0.1	0.1	0.6	4.6	21.2	3.8
Feet 2^+	0.6	0.4	0.2	1.2	6.6	21.2	4.4
Feet 3^+	---	0.1	---	0.2	5.8	5.2	0.9

Table 11.3 Age-standardized rates of osteoporosis in Bandungan people 25 years and older (EPOZ population as the standard) (in percentages)

	Zoetermeer	Bandungan	Band./Zoet.
Men			
Hands			
grade 2^+	5.8	9.7	1.7
grade 3^+	1.0	2.3	2.3
Feet			
grade 2^+	1.2	4.9	4.1
grade 3^+	0.2	0.7	3.5
Women			
Hands			
grade 2^+	16.1	39.2	2.4
grade 3^+	6.7	15.6	2.3
Feet			
grade 2^+	7.5	24.4	3.3
grade 3^+	1.7	10.2	6.0
Men + Women			
Hands			
grade 2^+	11.3	25.4	2.2
grade 3^+	4.0	9.4	2.4
Feet			
grade 2^+	4.6	15.3	3.3
grade 3^+	1.0	5.8	5.8

In table 11.3 age-standardized osteoporosis rates of the hands and feet are given for the Indonesian population sample. For Bandungan people above the age of 25 years osteoporosis of the hands is observed 1.7 to 2.4 times more often and of the feet 3.3 to 6 times more often than in the Dutch sample.

The major reason for this high osteoporosis rate at adult ages probably is the low intake of calcium from nutritional sources, together with a low calcium content of the local (well)

drinking water. In women an additional factor may be the fact that breast feeding of children in developing countries lasts for more than two years on the average, which together with a high parity rate might account for extra calcium losses. Furthermore while milk and milkproducts are the major calcium source in the Dutch food, Indonesian people do not take any of this after cessation of breastfeeding.

Lawrence (11.22) found grade 2 or more osteoporosis of the hands in 4% of the males and 13% of the females in the combined Leigh and Wensleydale population samples aged 15 years and over. In the feet these figures were 3% and 7% respectively, quite comparable to the Zoetermeer study. In a series of 7,300 hand X-rays from population samples in Europe and North America 1.9% of adult males and 8.8% of females were considered to have osteoporosis (11.23). But Lawrence also points out that observer variation might play an important role in the subjective assessment of osteoporosis in the metacarpals and metatarsals. It is therefore contemplated to re-evaluate the Dutch and Indonesian films by means of the Garn measurement and to try to obtain a food history of the Bandungan people and water samples of local wells to estimate its mineral content.

References

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11.21 Horseman A. Simpson M. The measurement of sequential changes in cortical bone geometry. Br J Radiol 1975;48:471-476.

11.22 Lawrence JS. Rheumatism in populations. Heinemann, London 1977:417.

11.23 Ibid. Page 411.

11.5.2 Miscellaneous

Among the 375 male and 537 female cases and controls seen in the phase four study, two (both males) had an enchondroma of one of the hand phalanges. This is the same rate as seen in the EPOZ-study.

Sequelae of fractures were regularly observed (table 11.4).

Chondrocalcinosis of the hands was seen in 1% of the handfilms. In the limited number of kneefilms made on request chondrocalcinosis was observed in 10%, but the same films showed radiological OA in 45%. Lawrence (11.24) observed chondrocalcinosis in 0.4% of the men and 0.1% of the women in Leigh and Wensleydale. In most European populations studied the rates stay below 1% and the prevalence figure is largely based on X-ray films of the knees. In this respect chondrocalcinosis seems to be rather prevalent in this Indonesian population sample.

Table 11.4 Miscellaneous radiological abnormalities in 912 Indonesian people 15 years and over (in percentages)

	Men	Women	Total
Radius fracture	0.5	1.7	1.2
Styloid fracture	2.4	2.4	2.4
Navicular fracture	0.3	0	0.1
Lunatomalacia	0.3	0	0.1
Enchondroma	0.5	0	0.2
Short metatarsal	0.5	0.7	0.7
Short metacarpal	0.8	0.7	0.8
Hand chondrocalcinosis	1.1	1.1	1.1
Knee chondrocalcinosis	8.7*	12.1**	10.7

* 2 out of 23 films made; 6/23 (26%) with grade 2 or more ROA

** 4 out of 33 films made; 19/23 (58%) with grade 2 or more ROA

Reference

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CHAPTER XII
CONLUSIONS AND RECOMMENDATIONS

12.1 Reappraisal of the COPCORD principle

In the present study only the first stage of the WHO-ILAR COPCORD has been executed. The second and third stage which have to do with the education of the (para)medical personnel and the improvement of the existing health care system in handling locomotor conditions will therefore not be discussed here.

The first stage of the programme has the following objectives:

1. To identify the magnitude of the problem concerning
    - 1.1 rheumatic complaints and conditions and disability,
    - 1.2 the need for support, treatment and prevention of handicap.
2. To identify the existing help resources such as
    - 2.1 official health care system,
    - 2.2 traditional health care system and
    - 2.3 self-help.
3. To investigate whether the existing help resources are
    - 3.1 effective in their endeavours,
    - 3.2 adequately equipped to cope with the existing need for help, treatment and prevention.

Re 1. Identification of the magnitude.

To determine the magnitude of the problem an instrument is needed which can be applied under various circumstances (urban-rural, populous-thinly populated), in different population groups (ethnic, religous, developing and developed etc.) and which should be able to provide quantitative results. This epidemiological instrument (phase 1) should be

- **simple** to be executed by preferably local lay people (primary health volunteers etc.) and can only concern simple items like complaints, self-stated disease, disability, kind of help sought etc.,
- **cheap** as the local resources in developing countries are limited,

- ideally **embedded** in the local health care system with its community workers and health care auxiliaries,
- **repeatable** in other parts of the country when e.g. the first survey discloses that the size of the problem (prevalence of disorders or disability, lack of support, inadequacy of the local health care system to cope with the problems) is great,
- executed in a population sample of sufficient size to give fair estimates for complaint and disability rates etc. (approximately 1,500 adult people).

Apart from the above-mentioned conditions such a study requires a medical **resource person** who

- has been trained in rheumatology,
- knows how to design and organize a survey,
- is being backed by the national health authorities,
- could be the person who is eventually going to treat or help the people, e.g. the local primary care physician,
- should have facilities to handle the data and calculate rates and associations and hence needs backing of the regional department of public health.

Re 2. Identification of the existing help resources.

What is locally available?

2.1 Official health care system:

- is there a qualified doctor and what is her/his level of training with regard to locomotor conditions (phase 3)?
- are there primary health workers or nurses who can be upgraded to execute part of the programme (phase 2)?
- are there community health workers who can be involved in the first phase of the study?
- is there a referral system to a district hospital with facilities such as physiotherapy?

2.2 Traditional health care system:

- how often is it utilized for rheumatic complaints and who is consulted for what?
- is it considered to be effective by the people?
- can it be upgraded to participate effectively in coping with the prevailing locomotor conditions?

2.3 Self-help system:
- do the people exercise self-help or neighbourhood help?
- are certain drugs freely available and if so are they safe?
- what local herbs, measures etc. are used?

Re 3. Investigation of help resources.

3.1 How effective is treatment by the primary health care system?
- is upgrading in rheumatology of the doctor necessary?
- are sufficient medicines available?
- what are the possibilities of referral to a qualified specialist?

3.2 What are minimum requirements in
- skills, equipment and treatment necessary to cope with 80% of the rheumatic problems encountered, such as disability, back and neck complaints and extra-articular rheumatism?
- the management of a (rare) patient with a severe condition such as rheumatoid arthritis, ankylosing spondylitis, gout, frozen shoulder and serious hip or knee problems (e.g. what are the laboratory facilities)?

Looking back at the constraints encountered during the execution of the survey in Bandungan a number of recommendations can be made:

1. The people to be examined should be identifiable for follow-up. Apart from an identification number, which is necessary to create a database, sufficient data should be available to locate the respondent, such as a detailed address (eventually by mapping the house), names of the father and the mother when surnames are variable, relation to head of the household etc. Ages are approximations in underdeveloped situations. They can be estimated within 5 years by means of "calendars of events", age of the children etc.

2. Data on occupation are relevant in relation to loss of work or income due to disability. Furthermore type of work could be a risk factor for problems of the musculoskeletal system. Occupation and participation in the workforce should therefore be described in such a way that the weight of labour can be categorized.

3. The questionnaires to be used should be carefully discussed with the interviewers and necessary translations into the local language and adjustments should be made.

4. The phase one questionnaire should concern primarily current complaints. Firstly, the present situation is relevant to the COPCORD principle and secondly a mixture of questions on present and past complaints confuses the respondent (and the interviewer) unless these questions are clearly separated in the questionnaire. Lastly the periods of time to which "now, present, current" or "ever, past" refer should be clearly delimitated.

5. The questionnaires should be tested in a pilot study in which the resource person validates the answers "on the spot" in small samples of the population to be investigated. The questionnaires should be adapted to the problems encountered and questions should be eliminated when they are not understood.

6. An important question is whether the people examined can cope with their locomotor problems. The word coping has a distinct connotation and quite often is difficult or impossible to translate or phrase in the local language. For the social (and medical) consequences of disability and handicap non-copers should have priority in being seen by (or referred to) a doctor.

7. The population sample should at least be of size 1,500 (adults) and eventually stratified for age when particularly in some age-groups relatively few people are available. Some local registry of people should be available or otherwise first a census of the population under consideration should be done.

8. The initial survey should not take much more time than 6 to 8 weeks, that is approx. 30 - 40 people seen per day and hence at least two interviewers would be required.

9. For a simple phase one study it would suffice to analyse findings by hand, but the number of questions should then be limited.

10. Major problems encountered during the phase one interview (such as severe disability) should be seen by the primary care doctor and therefore referred to the primary health center.

11. Some time-lag (e.g. 3 months) between consecutive study phases is helpful as trivial complaints will have disappeared.

12. When for the phase two study no qualified and upgraded nurse, midwife or primary health worker is available, the phases one and two can in part be combined.

13. The upgraded nurse or midwife should be able to distinguish major problems from minor ones. She does not need to establish diagnoses.

14. Minor problems eventually can be guided by the survey team (PHW or nurse) as to what to do (massage, analgesic treatment, exercises etc.).

15. The primary care doctor should have the skills and facilities to diagnose and treat (help) the major problems encountered, c.q. be able to consult a specialist.

16. As the COPCORD does not provide prevalence rates for the various rheumatological conditions, it could be contemplated to add to the phases one through three a phase four epidemiological survey. Such a survey designed to obtain prevalence rates would require additional funding for

- supplementary diagnostic facilities (x-rays, laboratory facilities etc),
- better facilities for statistical analysis (PC),

- physicians to establish diagnoses.

The time interval between the phases should be relatively short to reduce non-response. Instead of examining the whole population a case-control design can be used in which the cases are those people with complaints and the controls are selected from the remaining population.

By and large the Indonesian survey was successful in that it got splendid cooperation of the population, even at the stage that venapuncture was required. Employing the two PHWs for the interview survey was critical for the success of the venture for reasons that the two PHWs had served the area for more than three decades and knew almost all the adults by sight or name. They were both trusted by the people. An appeal by the PHWs to cooperate with the survey always got encouraging response and it was therefore not surprising to get a response rate of 99.8% for the phase two interview survey. The subdistrict had been exposed to western medicine for several decades and the community health center and its aid station had served the people for more than one decade. Organized or western medicine was already understood and well accepted by the people without reserve. That may be the reasons for the smooth cooperation from the local dignitaries, health professionals and the people. Furthermore the phases three and four respondents with current musculoskeletal pain were given an incentive of NSAID after the examination. Provision of transport to the place of examination and back home was another factor which increased the response rate which was further enhanced by home visits to the few respondents who refused to come.

When there was a rumour afloat that blood samples were sold abroad for high prices, it only slowed down the examination process as ultimately the PHWs were able to convince the people that the issue was not true and regain the respondents' confidence.

Representativeness and validity of the study results

Except for the different altitude of 750 - 950 meters above sea level, this rural population sample resembles eighty procent of the inhabitants of Central Java or even the islands of Java

and Madura, in average lifespan, sex distribution, income, race, religion, culture, and social class. Conclusions drawn from the results of the study are in general valid for the rural population of Java and possibly to a lesser degree for the rest of Indonesia. To our knowledge no comparable data have been published before which are representative for the population from which the sample was drawn. The few studies which have been conducted in Indonesia suffered from a heavy non-response. The fact that this study was carried out in a cool and damp climate could have biased the prevalence of certain severe rheumatological conditions (see chapter VI). Furthermore it would be advisable to conduct a similar study in an urban population. This has been accomplished in the city of Semarang since the Bandungan survey was finished.

Less successful was the inventory of the official health care resources with regard to the adequacy of coping with the existing need for help, support, treatment and prevention of handicap where musculoskeletal conditions were concerned. The primary care physicians were hardly trained in recognizing and managing rheumatological disease; the primary health center provided little facilities as to drug treatment except for NSAIDs and analgesics and for physiotherapeutical support the rheumatic sufferer was driven back to the traditional masseur. Referral by the primary care physician to the Regency Hospital (Rumah Sakit Kabupaten) is hardly a solution to this problem when the internist concerned still needs additional training to become an adequate consultant for rheumatic diseases.

12.2 Selection bias

In this study where the response to the interview survey was very high non-response bias is negligible where rheumatic complaints and the use of the available health care resources is concerned. In the subsequent phases a substantial percentage of non-response occurred, mainly due to the time-lag between consecutive surveys, disappearance of complaints and symptoms and clerical errors, which hampered identification of some respondents (chapter IV). Recommendations to improve this in future surveys have been given in paragraph 12.1. Nevertheless, depend-

ing on the way of calculation and adjusting for losses due to death and migration the final response rate was around 80%, which can be considered to be a high figure when compared to many other surveys. Apart from that the losses due to clerical errors most likely are random, but the higher non-response rate among younger people and the controls to some extent will be biased with regard to the presence of rheumatic complaints and conditions.

12.3 Rheumatological conditions

The prevalence rates for the observed rheumatological conditions and findings have been discussed in the various specific chapters (VI through XI). Some main concluding results are presented here.

- The rates for musculo-skeletal complaints are remarkably similar for most populations. The site distribution of complaints might differ from one population to the other.
- The prevalence rate for severe rheumatological disease such as rheumatoid arthritis (RA) and ankylosing spondylitis (AS) was low in this population when compared to studies in Caucasian populations. This could be due to an increased mortality on the one, and a low incidence on the other hand because of a different genetic make-up (e.g. a low prevalence of HLA-B27). On the other hand diseases like SLE and Reiter's disease did occur in this population sample.
- Some degenerative conditions, and particularly so of the spine, seem to be less frequent than in Caucasian people, but as radiographs of the cervical and lumbar spine were only obtained in few respondents such a comparison could not be made.
- Radiological degenerative abnormalities of the hands and feet vary in joint distribution from those observed in Europe and the USA, but the overall rates are comparable suggesting that (radiological) OA is ubiquitous and the observed low rates for clinical OA in Indonesia are due to observer error in establishing the diagnosis. For example knee OA seems to be prevalent in this squatting and mountaineering population.
- The rates for non-articular rheumatological conditions are

difficult to compare as systematic studies in other populations have not been performed and diagnostic criteria are not clearly defined. Nevertheless in this population sample tender spots, lumbago and shoulder fibrositis were the most prevalent conditions with rates of 33, 20 and 15 percent respectively, while conditions like cervical and lumbar spondylosis occurred in about 5% and sciatica and disc prolaps were encountered as often as in Holland and the UK (2 to 3%).

- Gout probably was a prevalent and under circumstances serious but preventable condition as was hyperuricaemia.
- Osteoporosis as judged subjectively from the hands and feet films occurred two to six times as often as in Caucasian population samples. As (subjectively) more sequelae of bone fractures were seen on the Indonesian films than on Dutch radiographs this finding could bear weight as to the relation between osteopenia and fractures.

It is therefore recommended to do further research into

- the reasons for the low observed prevalence and increased mortality of RA and AS (genetic make-up),
- the prevalence and determinants of knee OA,
- the determinants (genetic?) of the high prevalence of hyperuricaemia and gout. Simultaneously directions to the society can be given as to how to act in case of acute attacks of arthritis,
- the determinants of the high prevalence of osteopenia particularly in young women and the initiation of preventive nutritional measures.

12.4 Cost

In the first phase the COPCORD-design reduces the original population approached to approximately one quarter to be seen in the second phase and less than 15% to be examined by a doctor in phase three. Combining phases one and two might further reduce the cost but increases the number of people to be seen in phase three to twenty percent.

For epidemiological purposes a case-control design can be used, which starting from an initial sample size of 1,500 would

require about half of the sample to be examined in phase two and excluding trivial complaints about 40% or 600 people to be clinically examined in phase three. Such a study would then provide rates for symptomatic and symptomless rheumatological conditions in the target population.

The local cost for the phase two interview survey in Bandungan was US$ 4,000 for the total of 4,683 questionnaires analysed or US$ 0.85 per person unit excluding the expenses for photocopying, mailing and computer analysis of US$ 2,000 and excluding the loss of income of the author (resource person) in organizing and executing the survey. The total cost was US$ 1.28 per person unit. The local cost for rounding up and examining the people in phase four was US$ 3,200 for 1,179 persons or US$ 2.70 per person unit. Including radiology and venapuncture, but excluding serology it was US$ 11,530 for 946 people or US$ 12.20 per person unit. The expenses for the data management of phases two and four was US$ 2,000 in Rotterdam, the Netherlands. As the results from phase four could be converted to the total population of 4,683 people investigated in phase two the per respondent cost is less than US$ 4.50. The total cost of the enterprise can be set at ± US$ 21,000 including serology, data management and analysis again excluding the time expenditure and travel expenses of the author and the two expatriate experts who participated in the later phases of the study.

For the original COPCORD-design the cost would have been US$ 4,000 for the phase 1/2 study or US$ 0.85 per respondent while for the 841 people with complaints in phase two the cost in phase three would have been US$ 2,300 or US$ 2.75 per respondent. For analysis and reporting an additional US$ 2,000 would be necessary bringing the total expenditure to US$ 8,300 for 4,683 respondents seen or US$ 1.77 per respondent. As a sample size of 1,500 would be sufficient and adjusting for the relatively higher per respondent cost the total cost for 1,500 people would be US$ 3,750 or US$ 2.50 instead of US$ 1.77. Including radiology and serology in a case-control design of 600 people would increase the expenses to US$ 9,000 or US$ 6 per respondent.

It is obviously feasible to apply the COPCORD principle in cheap population surveys of two or three phases without radiology and serology and provide more or less valid data on the preval-

ence rate of almost all the common rheumatic disease entities based on international accepted epidemiological criteria and simultaneously identify the magnitude of the problem of rheumatic diseases in the community and the perceived need of treatment of the individual patient. Even including radiology and serology, the cost can be considerably reduced by a case-control study design where only (a sub-sample of) the cases and an (age- and sex-matched) controlgroup are exposed to radiology and venapuncture.

SUMMARY

This thesis deals with a population study on rheumatic diseases in the subdistrict Bandungan, Central Java, Indonesia. It is part of a series of epidemiological surveys executed according to the World Health Organisation - International League Against Rheumatism (WHO-ILAR) initiative for a Community Oriented Programme for the Control Of Rheumatic Diseases (COPCORD). Comparable studies have been done in the Philippines and Australia and one is being executed presently in Malaysia.

In Chapter I a description is given of the geography, history, demography, economy and health situation of Indonesia, (Central) Java and the subdistrict Bandungan in part of which the study was performed.

Chapter II gives the background and objectives of the COPCORD. Essentially the COPCORD is a three stages programme. In stage one the magnitude of the problem concerning rheumatic conditions and resulting disability, the need of the rheumatic sufferers for support and treatment and the capability of the local health care facilities for coping with musculoskeletal conditions are inventoried. Stage two deals with education of the (para)medical primary health care personnel and stage three is directed towards improvement of the health situation of the patient him/herself through the existing official and traditional care systems.

Stage one is designed as a three phases relatively cheap epidemiological instrument. In phase one local (voluntary) health workers interview the target population using a questionnaire which deals with current joint, neck and back complaints, with disability and the utilisation of the available official, traditional and self-help systems. In phase two a nurse, midwife or primary health worker upgraded in knowledge about musculoskeletal conditions examines the cases with complaints and/or disability from phase one and separates those who due to their condition require professional medical care (diagnosis, treatment) to be referred to the primary health phsysician, who in turn might consult a specialist in a near-by hospital.

The Bandungan survey combined for practical reasons phases one and two, while phase three was complemented by a phase four epidemiological study in which clinical, radiological and serological diagnoses were established in the cases from phase two supplemented by a control group half the size. In this way it was possible to obtain prevalence rates for a number of major rheumatological diagnoses in the original target population.

Chapter III describes the target population of 4,693 adults, the method of registration, the examination, the questionnaires used and the laboratory procedures applied. Much emphasis is given to the experienced constraints. Particularly problems with the identification, translation and interpretation were encountered. Checking of the questionnaires on the spot and discussing the errors with the interviewers (primary health workers) considerably improved the quality of the data.

Chapter IV gives the response rates in the various phases of the study. Where the people were concerned the response rates were high. Allowing for losses due to death and migration the response rates in phases one/two, three and four were 99.8, 93.7 and 83.3% respectively. Due to clerical errors finally only 72.3 to 80.4 percent of the proformas could be linked between phases two and four and only 69 to 77 percent of the proformas were available for analysis of all three phases. The losses to follow-up were definitely also due to the long time-lag between phases two and three (20 months) and three and four (13 months). Non-response was greater among males, cases and younger people.

Because of the case-control design age- and sex-specific conversion factors could be calculated with which the observed nominators in phase four were multiplied in order to be able to calculate prevalence rates in phase two.

Chapter V in principal describes the results of the phase one questionnaire survey on current complaints, disability and perceived need for help, supplemented with some questions from phase two regarding past complaints, possible causes and duration of complaints. The prevalence rates of complaints were remarkably similar when the Indonesian survey was compared with the COPCORD

survey in the Philippines and population studies in the UK (Leigh and Wensleydale) and the Netherlands (Epidemiological Preventive Organisation Zoetermeer - EPOZ). Distribution over the various pain sites - and particularly so the neck and back - varied between populations, back and neck complaints being far more prevalent in Caucasians.

Past acute pain in the big toe with swelling and redness and the pain disappearing within two weeks without treatment occurred in three men and one woman, suggesting gout (see chapter X). Knees, shoulders, hips and ankles were the most frequently affected joints in the past.

The disability rate for either dressing, lifting, carrying or walking was low (2.8%), but problems with other activities of daily life were not asked for.

Ninety percent of the people with complaints said that they needed treatment. Of these more than 60% had visited the community health center and more than 85% had sought help from traditional healers or self-medication. Nearly 30% had utilized three or more traditional care facilities. More than half of the people bought antirheumatic drugs which contained prednison, phenylbutazon and paracetamol and were freely available! Further analysis revealed that the expected annual per capita consumption of this drug irrespective the presence of complaints, was 12 tablets. Since the Bandungan survey combinations of corticosteroids and non-steroidal anti-inflammatory drugs have officially been banned in Indonesia.

Chapter VI deals with the occurrence of rheumatoid arthritis (RA) in this population. All 8 cases of severe and definite RA observed during the phase two study had died twenty months later. In phases three and four no new cases of probable or definite RA were seen. The prevalence rate of probable + definite RA in the original population sample was 0.3% (0.2% definite) with a nine to four female to male ratio.

Radiological erosive arthritis (EA) occurred in 0.1% of the men and 1.2% of the women. All were considered to be false-positive. The latex fixation test (LFT) was positive within the limit of 5% set as a maximum for normal populations. The Waaler-Rose test (HEAT), however, was positive in nearly 13%. All ob-

served positive titers in phase four were false-positive.

The low rate for RA in Indonesia is comparable with the rates observed in other developing countries, particularly in Africa. Different from the African results are the low rates for EA in Indonesia and the high rate for the HEAT, only comparable with the survey in Lesotho. It is suggested that this latter finding in Indonesia could eventually be the result of past exposure to yaws.

In Chapter VII the prevalence rates of spinal disorders are described. Ankylosing spondylitis was not seen in this population. Cervical and lumbar spondylosis occurred in 5 and 4% respectively, considerably lower than in Caucasian populations. Lumbago was four times more prevalent than in the EPOZ study(20% versus 5%), but disc prolaps and sciatica occurred about as often as in the Dutch survey(2.3% and 2.9% resoectively).

The sensitivity, specificity and predictive value of abnormalities on physical examination for the various clinical diagnoses are presented in a number of tables. With exceptions the results suggest that the examining physicians in general derived their diagnosis from the abnormalities observed on physical examination.

There was a gross underestimation (Chapter VIII) of clinical localized and generalized osteoarthritis (OA). This was due to observer bias, which could be concluded from the fact that based on the number of requested knee radiographs at least 14% of the adult people suffered from clinical and 4.5% from radiological knee OA.

Heberden's nodes and bony enlargement of the DIPs occurred in 2.9 and 2.3% respectively and were 1.4 and 1.9 times more prevalent in women. Heberden's nodes were more prevalent than in Liberia and Nigeria, but less than in all other populations surveyed.

With exception of some joint(group)s the age standardized rates for radiological OA of the hands and feet joints were similar in Indonesia and the Netherlands.

In Chapter IX the prevalence rates of shoulder fibrositis

(13.9% in men and 14.9% in women) and epicondylitis (5% in men and 6.1% in women) are presented. Shoulder fibrositis occurred more often on the right side as did epicondylitis. Shoulder fibrositis was far more prevalent in the Indonesian population than periarticular fibrositis in the EPOZ population (3.3 times more often in men and 2.4 times more often in women), but the diagnostic evaluation of shoulder conditions was different in the two studies. Epicondylitis occurred 2.5 times (men) and 1.5 times (women) more often in the Indonesian population.

Tender spots were present in 29% of the men and 35.5% of the women (3.3 times more often than muscular spasm in the EPOZ men and 1.9 times more often than muscular spasm in the EPOZ women).

Except for a high specificity limited shoulder movements were weakly associated with shoulder fibrositis, but tender spots had a high sensitivity, specificity and predictive value for this condition. Pain on pressure of the elbow condyles exhibited a moderate (49.3%) to good (100%) sensitivity, reasonably high (79 to 98.5%) specificity, and a moderate (44.9 to 79.6%) predictive value for epicondylitis.

Chapter X deals with gout. A case report is given of a patient with severe, chronic, tophaceous gout. Based on clinical diagnoses in phase four the prevalence of gout was 1.7% in men and 0.05% in women. However, only 50% of the diagnosed cases were hyperuricaemic. Therefore the prevalence of gout would halve when hyperuricaemia should be a requirement to establish the diagnosis and become 0.9%, still considerably higher than in most Caucasian populations.

Hyperuricaemia occurred in 24.3% of the men and 11.7% of the women. In men it reached values comparable to those found among the Filipinos, Chamorros of the Mariana Islands, New Zealand Caucasians and Canadian Chinese. Among other Caucasians the rates vary between 5 and 30%. Mean serum uric acid values were 0.7 mg/100 ml higher than in the EPOZ study in both men and women. They were of the same magnitude (6.2 mg/100 ml in men and 5.2 mg/100 ml in women) as in the Filipinos living in the Philippines, Hawaii and Alaska; the Malays, Tamils and Chinese living in Malaysia and the Caucasians of New Zealand.

As meat and alcohol consumption are low to negligible in

Bandungan, obesity is absent and social class is monostructured, the likelihood is that hyperuricaemia and gout in this Indonesian population sample are genetically determined.

Chapter XI describes miscellaneous conditions observed in the Bandungan survey. There was one case of SLE and two cases of Reiter's disease. Burned out cases of RA were not seen.

An interesting observation was the 2% prevalence of fibrous nodules of the shoulder girdle in man but not in women, most likely the result of carrying heavy loads by means of a resilient wooden pole across the shoulder.

Osteoporosis as subjectively judged from the hand and foot films occurred two to six times more often in the Indonesian males and females as compared to the people in the EPOZ study. It was particularly prevalent in young women where it occurred 18 times more often in the metacarpals and 12 times more often in the metatarsals in the Indonesian sample. Indonesian men of corresponding age showed 3 to 4 times more osteoporosis of the hands and feet than their Dutch counterparts. These figures suggest that Indonesian women at young age suffer from extra calcium losses, probably due to prolonged breast feeding.

Lastly a number of other radiological abnormalities are reported.

Finally in Chapter XII the COPCORD principle is reappraised and based on the experience with the Indonesian survey recommendations for future studies are made. Despite the problems encountered the Indonesian COPCORD study can be seen as a successful epidemiological enterprise with likely little selection bias. For the first time prevalence rates for a number of rheumatological diagnoses have been established in a large Indonesian population sample and at a very low cost when compared to corresponding studies performed in developed countries.

At the same time it has become clear that the local primary health care facilities are insufficiently equipped to cope with the variety of rheumatological diagnostic and therapeutic problems. Further education of the (para)medical personnel is necessary, particularly because the burden on the society is great, be it of lesser magnitude than that of infectious diseases.

SAMENVATTING

In dit proefschrift worden de resultaten beschreven van een populatie onderzoek op reumatische ziekten in het subdistrict Bandungan in Midden-Java, Indonesië. Deze studie is onderdeel van een serie epidemiologische onderzoeken die op grond van het Community Oriented Programme for the Control Of Rheumatic Diseases (COPCORD) van de Wereldgezondheidsorganisatie en de International League Against Rheumatism (WHO-ILAR) worden uitgevoerd. Vergelijkbaar onderzoek is in de Philippijnen en Australië verricht en vindt op dit moment in Maleisië plaats.

In **Hoofdstuk** I wordt een beschrijving gegeven van de geografie, geschiedenis, demografie, economie en gezondheidssituatie in Indonesië, (Midden) Java en het subdistrict Bandungan, waar in een deel van de bevolking de studie werd uitgevoerd.

Hoofdstuk II beschrijft de achtergrond en doelstellingen van het COPCORD, een programma dat in feite uit drie onderdelen bestaat. In het eerste stadium worden gegevens verzameld over de omvang van het probleem inzake reumatische aandoeningen, de hierdoor ontstane beperkingen, de behoefte van de lijders aan reumatische klachten aan hulp en behandeling en de mogelijkheden van de locale gezondheidszorg organisatie om aan deze problematiek tegemoet te komen. Het tweede stadium betreft opleiding van het eerstelijns (para)medisch personeel en het derde onderdeel beoogt een verbetering van de gezondheidssituatie van de patient zelf te bewerkstelligen binnen de bestaande officiële en traditionele zorgsystemen.

Het eerste onderdeel is ontworpen als een relatief goedkoop epidemiologisch instrument dat weer uit drie fasen bestaat. In de eerste fase ondervragen lokale vrijwilligers de doelpopulatie. Zij maken hierbij gebruik van een vragenlijst die de aanwezige gewrichts-, nek- en rugklachten, beperkingen en het gebruik van de beschikbare officiële, traditionele en zelf-hulp systemen inventariseert. In de tweede fase onderzoekt een verpleeg(st)er, verloskundige of eerstelijns gezondheidswerk(st)er, die nascholing heeft gekregen in aandoeningen van het bewegingsapparaat de

respondenten met klachten of beperkingen uit de eerste fase en verwijst degenen die op grond van hun aandoening dit behoeven (b.v. om diagnostische of therapeutische redenen) naar de eerstelijns arts, die op zijn beurt een specialist kan consulteren in een nabij gelegen hospitaal.

Het onderzoek in Bandungan combineerde om praktische redenen de eerste en tweede fase, terwijl fase drie werd aangevuld met een fase vier epidemiologisch onderzoek waarin klinische, radiologische en serologische diagnosen werden vastgesteld in de personen met klachten (cases) uit de tweede fase aangevuld met een controle groep van mensen zonder klachten van de halve omvang. Op deze manier was het mogelijk om prevalentie cijfers van de belangrijkste reumatologische aandoeningen te verkrijgen in de oorspronkelijke steekproef.

Hoofdstuk III beschrijft de doelpopulatie van 4693 volwassenen, de wijze van registratie en onderzoek, de gebruikte vragenlijsten en de toegepaste laboratorium technieken. Veel aandacht wordt geschonken aan de ondervonden moeilijkheden. Met name waren er problemen met de identifikatie, vertaling en interpretatie van de vragen. Het ter plaatse controleren van de vragenlijsten en vervolgens bespreken van de gemaakte fouten met de eerstelijns gezondheidswerkers verbeterde de kwaliteit van de gegevens aanzienlijk.

In **hoofdstuk IV** zijn de respons rates in de verschillende fasen van onderzoek vermeld. De opkomst van de mensen was groot. Rekening houdend met verliezen als gevolg van overlijden en migratie waren de respons rates voor het eerste, tweede en derde onderzoek respectievelijk 99,8, 93,7 and 83,3 procent. Als gevolg van administratieve fouten konden uiteindelijk slechts 72,3 tot 80,4 procent van de statussen afkomstig uit de fasen twee en vier gekoppeld worden. Voor analyse van alle drie de onderzoeken waren slechts 69 tot 77 procent van de statussen koppelbaar. De verliezen in de vervolg onderzoeken waren zeker ook het gevolg van de lange tijdsintervallen tussen de fasen twee en drie (20 maanden) en drie en vier (13 maanden). Meer non-response trad op onder de mannen, de cases en de jongere mensen.

Als resultaat van het case-controle ontwerp konden door

middel van leeftijds- en geslachtsspecifieke omrekeningsfactoren de tellers van de prevalentiebreuken in fase twee worden bepaald.

Hoofdstuk V beschrijft in eerste instantie de resultaten van de vragenlijst van de eerste fase betreffende aanwezige klachten, beperkingen en de gevoelde behoefte aan hulp, aangevuld met sommige vragen uit het tweede fase onderzoek inzake klachten vroeger, mogelijke oorzaken en duur van de klachten. De prevalentiecijfers inzake klachten kwamen opmerkelijk overeen met die gevonden in de COPCORD studie in de Philippijnen en populatie studies in het Verenigd Koninkrijk (Leigh en Wensleydale) en Nederland (Epidemiologisch Preventief Onderzoek Zoetermeer-EPOZ). De verdeling naar localisatie - en met name pijn in de nek en (lage) rug - varieerde tussen populaties. Rug- en nekklachten kwamen veel meer voor bij blanken.

Acute pijn vroeger in de grote teen, gepaard gaande met zwelling en roodheid en waarbij de pijn zonder behandeling binnen twee weken verdween werd gevonden bij drie mannen en één vrouw, hetgeen suggestief was voor de aanwezigheid van jicht (zie hoofdstuk X). Knieën, schouders, heupen en enkels bleken de meest frekwent in het verleden aangedane gewrichten te zijn.

Beperkingen voor hetzij aankleden, tillen, dragen of lopen werden slechts in 2,8% van de populatie gevonden. Hierbij dient te worden opgemerkt dat naar andere beperkingen van de activiteiten van het dagelijks leven niet werd gevraagd.

Negentig procent van de mensen met klachten verklaarde dat zij meenden behandeling nodig te hebben. Van deze laatsten hadden meer dan 60% het plaatselijk gezondheidscentrum bezocht en meer dan 85% had hulp in het traditionele zortgsysteem gezocht of zich eigen medicijnen verschaft. Bijna 30% had gebruik gemaakt van drie of meer traditionele geneeswijzen. Meer dan de helft van de mensen kocht antireumatica die prednison, fenylbutazon en paracetamol bevatten en vrijelijk in de dorpswinkel konden worden verkregen! Nadere analyse leerde dat de verwachte jaarlijkse consumptie per hoofd van de bevolking ongeacht de aanwezigheid van klachten 12 tabletten bedroeg. Sinds dit bekend is zijn combinaties van corticosteroiden en niet steroidale anti-inflammatoire geneesmiddelen officieel in Indonesië verboden.

Hoofdstuk VI behandelt het voorkomen van reumatoide artritis (RA) in deze bevolking. Alle 8 gevallen van ernstige zekere RA die gedurende het eerste (fase twee) onderzoek waren gezien bleken 20 maanden later overleden te zijn. In de derde en vierde fase van het onderzoek werden geen nieuwe patienten met waarschijnlijke of zekere RA opgespoord. De prevalentie van waarschijnlijke + zekere RA bedraagt in de oorspronkelijke bevolking derhalve 0,3% (0,2% zekere RA) met een 9 : 4 verhouding tussen vrouwen en mannen.

Radiologische erosieve arthritis (EA) kwam in 0,1% van de mannen en 1,2% van de vrouwen voor. Geen van deze personen had voldoende klachten of verschijnselen om gecategoriseerd te worden als RA. Zij konden derhalve beschouwd worden als fout-positief te zijn. De seropositiviteit van de latex fixatie test (LFT) bleef binnen het 5 procents maximum dat voor normale populaties is vastgesteld. De Waaler-Rose test (HEAT) was echter in bijna 13% positief. Alle seropositieve personen konden als fout-positief worden aangemerkt.
De lage frekwentie van RA op populatienivo in Indonesië is vergelijkbaar met de prevalenties waargenomen in andere ontwikkelingslanden, in het bizonder in Afrika. Anders dan in Afrika werden in de Indonesische studie lage frekwenties voor EA gevonden en een hoge frekwentie voor de HEAT. Dit laatste fenomeen werd alleen in Lesotho waargenomen. Gesuggereerd wordt dat deze serologische bevinding in de indonesische populatie het gevolg zou kunnen zijn van blootstelling in het verleden aan framboesia.

In **hoofdstuk VII** worden de prevalenties van aandoeningen van de wervelkolom beschreven. Spondylitis ankylopoetica werd in deze populatie niet gezien. Cervicale en lumbale spondylarthrose werd in respectievelijk 5 en 4 procent vastgesteld, hetgeen veel lager is dan in blankebevolkingen. De prevalentie van lumbago was viermaal hoger dan in het EPOZ (20% tegen 5%), maar een hernia nuclei pulposi en ischias werden ongeveer even vaak gezien als in het nederlandse onderzoek (respectievelijk 2,3 en 2,9%).

De sensitiviteit, specificiteit en predictieve waarde van afwijkingen gevonden bij lichamelijk onderzoek voor de verschillende klinische diagnosen worden in een aantal tabellen weergegeven. Met uitzonderingen suggereren de resultaten dat de onderzoe-

kende artsen in het algemeen hun diagnosen afleiden van de afwijkingen die zij bij lichamelijk onderzoek vinden.

De klinische diagnosen gelocaliseerde en gegeneraliseerde osteoarthrose werden schromelijk onderschat (**hoofdstuk** VIII). Dit was het gevolg van waarnemers bias, hetgeen kon worden afgeleid uit het aantal kniefoto's dat op verzoek van de onderzoekende artsen werd gemaakt en waaruit bleek dat tenminste 14% van de volwassen bevolking lijdende was aan een klinische en 4,5% aan een radiologische knie arthrose.

Noduli van Heberden en benige verbreding van de DIP-gewrichten werden in respectievelijk 2,9 en 2,3% aangetroffen en kwamen 1,4 en 1,9 maal meer voor bij de vrouwen. Noduli van Heberden kwamen meer voor dan in Liberia en Nigeria, maar minder dan in alle andere hierop onderzochte populaties.

Met uitzondering van enkele gewricht(sgroep)en waren de voor de leeftijd gestandaardiseerde prevalenties van radiologische arthrose van de hand- en voetgewrichten gelijk in Indonesië en Nederland.

In **hoofdstuk** IX worden de prevalenties van schouder fibrositis (13,9% bij de mannen en 14,9% bij de vrouwen) en epicondylitis (5% in mannen en 6,1% in vrouwen) beschreven. Fibrositis kwam evenals epicondylitis vaker aan de rechter zijde voor. Schouder fibrositis werd in deze indonesische bevolking veel vaker gezien dan periartritis humeroscapularis in de EPOZ-bevolking (3,3 maal vaker bij mannen en 2,4 maal meer bij vrouwen). Hierbij moet worden vermeld, dat de diagnostische evaluatie van schouder afwijkingen in de twee onderzoeken verschillend was. Epicondylitis kwam 2,5 (mannen) maal en 1,5 (vrouwen) maal meer voor in de indonesische bevolking.

Pijnlijke drukpunten werden in 29% van de mannen en 35,5% van de vrouwen aangetroffen (3,3 maal meer dan de diagnose "spierspasme" in EPOZ-mannen en 1,9 maal meer dan spierspasme in EPOZ-vrouwen). Met uitzondering van een hoge specificiteit waren beperkingen van de beweeglijkheid van het schoudergewricht zwak geassocieerd met schouder fibrositis. Pijnlijke drukpunten daarentegen hadden een hoge sensitiviteit, specificiteit en predictieve waarde voor deze aandoening. Drukpijn van de elleboogs-

condylen liet een matige (49,3%) tot goede (100%) sensitiviteit zien, een redelijk hoge (79 tot 98,5%) specificiteit en een matige (44,9 tot 79,6%) predictieve waarde voor de diagnose epicondylitis.

Hoofdstuk X behandelt jicht. De casuistiek van een patient met ernstige, chronische, topheuze jicht wordt vermeld. Gebaseerd op de klinisch gestelde diagnosen in fase vier was de prevalentie van jicht 1,7% bij de mannen en 0,05% bij de vrouwen. Slechts 50% van de klinisch gediagnosticeerde jichtgevallen had een verhoogd serum urinezuur gehalte. De prevalentie zou derhalve worden gehalveerd wanneer hyperuricaemie een voorwaarde was om de diagnose te stellen en dan 0,9% worden, hetgeen nog altijd aanzienlijk hoger is dan in de meeste blanke bevolkingen.

Hyperuricaemie kwam in 24,3% van de mannen en in 11,7% van de vrouwen voor. De mannelijke prevalentie is vergelijkbaar met die gevonden in Filipino's, de Chamorro's van de Mariannen Eilanden, de blanken van Nieuw Zeeland en de canadese Chinezen. Bij andere blanke volkeren schommelen de frequenties tussen 5 en 30%.

De gemiddelde serum urinezuur gehaltes waren 0,7 mg/100 ml hoger dan in het EPOZ in zowel mannen als vrouwen. Deze gemiddelden (6,2 mg/100 ml in mannen en 5,2 mg/100 ml in vrouwen) waren overeenkomstig aan die gevonden bij Filipino's woonachtig in de Philippijnen, Hawaii en Alaska; de Maleisiërs, Tamils en Chinezen die in Maleisië wonen en de blanken van Nieuw Zeeland.

Aangezien het gebruik van vlees en alcohol laag tot verwaarloosbaar is in Bandungan, zwaarlijvigheid afwezig en de sociale structuur eenvormig, lijkt het waarschijnlijk dat de relatief hoge frekwentie aan hyperuricaemie en jicht in de indonesische steekproef genetisch bepaald zijn.

Hoofdstuk XI beschrijft diverse sporadisch aangetroffen aandoeningen in Bandungan. Er was één geval van gesystematiseerde lupus erythematosus en twee patienten met de ziekte van Reiter. Uitgebluste reumatoide artritis werd niet gezien.

Een interessante observatie was de prevalentie van 2% fibreuze schouder noduli bij mannen, maar niet bij vrouwen, hoogstwaarschijnlijk als gevolg van de 'pikolan' (het dragen van zware lasten aan de uiteinden van een veerkrachtige bamboestok,

die afwisselend op de linker en schouder wordt gelegd).

Osteoporose zoals die subjectief werd geëvalueerd op grond van de films van handen en voeten kwam twee tot zes maal meer voor in de indonesische mannen en vrouwen in vergelijking met de mensen in het EPOZ. Osteoporose kwam met name bij indonesische jonge vrouwen veel voor (18 maal vaker in de metacarpalia en 12 maal frekwenter in de metatarsalia dan in EPOZ. Indonesische mannen van overeenkomstige leeftijd hadden 3 tot 4 maal meer osteoporose van handen en voeten dan hun nederlandse tegenhangers). Deze cijfers suggereren dat jonge indonesische vrouwen te lijden hebben van extra kalkverlies, mogelijk als gevolg van langdurige borstvoeding simultaan met een te geringe opname uit de voeding.

Tenslotte worden nog enkele andere radiologische afwijkingen vermeld.

In **hoofdstuk XII** tenlotte wordt het COPCORD principe opnieuw bezien en worden gebaseerd op de indonesische ervaring aanbevelingen gedaan voor toekomstige studies. Ondanks de vele problemen kan de indonesische COPCORD studie gezien worden als een succesvol verlopen epidemiologische onderneming met weinig selectie bias. Voor de eerste maal zijn er prevalenties vastgesteld voor een aantal reumatologische diagnosen in een grote indonesische bevolkingssteekproef tegen zeer lage kosten wanneer die worden vergeleken met overeenkomstige studies in ontwikkelde landen.

Tegelijkertijd is het duidelijk geworden dat de locale eerstelijns gezondheidszorg voorzieningen niet voldoende in staat zijn om met een verscheidenheid aan reumatologische diagnostische en therapeutische problemen om te gaan. Nascholing van (para)medisch personeel is noodzakelijk, met name omdat de last van aandoeningen van het bewegingsapparaat op de maatschappij groot is, zij het van minder omvang dan die van de infectieziekten.

RINGKASAN

Tesis ini hanya menguraikan tentang perencanaan, proses penelitian dan hasil penelitian penyakit rematik dalam masyarakat di Kemantren Bandungan, kacamatan Ambarawa, Kabupaten Semarang, Jawa Tengah. Survei ini merupakan bagian dari serentetan penyelidikan epidemiologi dalam merealisasi program kemasyarakatan Organisasi Kesehatan Dunia (World Health Organization = WHO) - Liga Internasional Terhadap Rematik (International League Against Rheumatism = ILAR) dalam pengendalian penyakit rematik (Community Oriented Programme for the Control Of Rheumatic Diseases = COPCORD). Penelitian-penelitian pembanding telah dilaksanakan di Philipina, Australia, dan sedang berlangsung di Malaysia.

Bab I menguraikan tentang ilmu bumi, sejarah, demografi, ekonomi dan kesehatan Indonesia, pulau Jawa, propinsi Jawa Tengah, Kabupaten Semarang dan Kemantren Bandungan, dimana penyelidikan ini telah dilakukan.

Bab II menerangkan tentang latar belakang dan sasaran dari COPCORD. Kerangka COPCORD berbentuk program tiga tingkat. Dalam tingkat pertama besarnya masalah penyakit rematik dalam masyarakat dan ketidakmampuan yang ditimbulkannya, kebutuhan penderita akan bantuan dan pengobatan dan kemampuan Pusat Kesehatan Masyarakat (Puskesmas) untuk menanggulangi kelainan muskulo-skeletal diinventarisasi. Tingkat kedua meliputi pendidikan tenaga paramedik dan medik dalam penanganan penyakit rematik yang lebih handal. Tingkat ketiga berujud perbaikan kesehatan penderita melalui Puskesmas dan pengobatan tradisionil.

Tingkat pertama disusun dalam tiga tahap sehingga relatip murah sebagai alat epidemiologi. Dalam tahap pertama seorang promotor kesehatan desa (prokesa) mewawancarai penduduk sasaran dengan kwesioner meliputi nyeri sendi, - tengkuk, - punggung,- pinggang, ketidakmampuan, dan pemanfaatan sarana bantuan yang tersedia baik yang resmi (dokter, perawat, pembantu perawat), tradisionil (tukang pijit, dukun, jamu, tusuk jarum) maupun pertolongan terhadap dirinya sendiri (mengobati dirinya sendiri dengan membeli obat). Dalam tahap kedua seorang perawat, bidan

atau pembantu perawat yang sudah ditatar tentang kelainan muskulo-skeletal mewawancarai dan memeriksa kasus dengan keluhan nyeri/atau ketidakmampuan dari tahap pertama dan memisahkan mereka yang karena keadaannya perlu perawatan lebih lanjut (diagnosa, pengobatan) untuk dirujuk ke dokter Puskesmas. Dokter Puskesmas mungkin akan merujuk penderita ke spesialist di rumah sakit Kabupaten.

Berdasarkan alasan praktis penelitian Bandungan menyatukan tahap pertama dengan tahap kedua, sedangkan tahap ketiga dilengkapi dengan tahap keempat yang mencakup penelitian epidemiologi, dimana diagnosa klinik, radiologik dan serologik ditegakkan pada kasus dari tahap kedua dengan tambahan kontrol sejumlah separuh dari kasus. Secara demikian dimungkinkan untuk mendapatkan angka prevalensi dari beberapa kelompok utama penyakit rematik pada penduduk sasaran tahap pertama/kedua.

Bab III membicarakan penduduk sasaran yang berjumlah 4693 orang berumur 15 keatas, cara pendaftaran penduduk sasaran, cara pemeriksaan, kwesioner yang dipakai dan tatalaksana laboratorium. Kesulitan dan keterbatasan survei yang dialami dibicarakan, terutama masalah pengenalan penduduk sasaran, penterjemahan dan interpretasi kwesioner. Pencocokan kwesioner di lapangan dan musyawarah tentang kesalahannya dengan pembantu perawat sangat memperbaiki mutu data yang dikumpulkan.

Bab IV memperlihatkan response rate dari beberapa tahap penyelidikan ini. Angka response penduduk cukup tinggi. Kehilangan responden karena kematian dan perpindahan masih menghasilkan angka response dari tahap pertama/kedua, ketiga dan keempat sejumlah 99.8%, 93.7% dan 83.3%. Kekeliruan administrasi menyebabkan hanya 72.3% - 80.4% kwesioner yang dapat dicocokkan antara tahap satu/dua dan empat. Untuk ketiga tahap sekaligus hanya 69 - 77% dari kwesioner yang cocok satu tahap dengan tahap lain untuk dianalisa. Kehilangan responden juga disebabkan oleh jangka waktu yang panjang antara tahap satu/dua dan tiga (20 bulan) dan tahap ketiga ke tahap keempat (13 bulan). Non-response paling banyak terdapat pada pria, kasus dan kaum muda.

Karena pola penelitian adalah kasus-kontrol, faktor konversi yang spesifik untuk golongan umur dan jenis kelamin dapat

dikalkulasi dengan mana nominator dari tahap empat dapat dikalikan dengan faktor konversi ini untuk mendapatkan angka prevalensi penduduk sasaran tahap ppertama/kedua.

Bab V menguraikan hasil dari kwesioner tahap pertama tentang keluhan, ketidakmampuan dan kebutuhan akan pengobatan, ditambah dengan beberapa pertanyaan dari kwesioner tahap kedua tentang keluhan yang lalu, kemungkinan penyebab dan lamanya keluhan nyeri. Angka prevalensi keluhan nyeri cukup mirip satu sama lain apabila hasil penyelidikan Indonesia dibandingkan dengan survei COPCORD tahap pertama di Philipina, penelitian masyarakat di Inggeris (Leigh dan Wensleydale) dan Negeri Belanda (Epidemiological Preventive Organisation Zoetermeer - EPOZ). Lokasi nyeri terutama di tengkuk, punggung dan pinggang bervariasi antara satu dan lain bangsa, dimana keluhan nyeri tengkuk,- punggung dan - pinggang lebih sering terdapat pada bangsa kulit putih (Eropa).

Nyeri akut yang lalu di sendi ibu jari kaki dengan pembenkakan, kulit diatasnya kelihatan kemerah-merahan, teraba hangat dan nyeri menghilang dalam waktu dua minggu ditemukan pada tiga pria dan satu wanita. Terdapat kesan mereka menderita penyakit pirai (lihat bab X). Lutut, sendi bahu, sendi paha dan pergelangan kaki merupakan sendi yang paling sering dihinggapi nyeri waktu yang lalu.

Angka ketidakmampuan untuk berpakaian, mengangkat barang, membawa barang dan berjalan cukup rendah (2.8%), tetapi cukup berarti untuk yang bersangkutan karena 52.2% berumur dibawah 55 tahun. Masalah ketidakmampuan dalam kegiatan hidup sehari-hari lainnya tidak ditanyakan.

Sembilan puluh prosen penduduk desa dengan keluhan nyeri menyatakan membutuhkan pengobatan. Dari mereka 60% pernah mengunjungi Puskesmas dan lebih dari 85% pernah berusaha dengan pengobatan tradisionil atau mengobati dirinya sendiri dengan membeli obat. Hampir 30% dari mereka pernah memanfaatkan tiga atau lebih sarana pengobatan tradisionil sekaligus (pijit, jamu, dukun, tusuk jarum). Lebih dari separuh penderita membeli obat antirematik yang mengandung prednison, fenilbutazon, dan parasetamol yang dapat dibelinya tanpa resep. Analisa lebih lanjut mengungkapkan bahwa pemakaian obat campuran ini per

kapita dapat mencapai 12 tablet tiap tahun terlepas dari adanya nyeri muskulo-skeletal. Sejak survei Bandungan kombinasi obat kortikosteroid dengan anti-inflamasi non-steroid (AINS) secara resmi dilarang beredar.

Bab VI membicarakan tentang artritis rematoid. Semua 8 kasus artritis rematoid definit yang ditemukan dalam penelitian tahap satu/dua sudah meninggal 20 bulan kemudian. Dalam penyelidikan tahap ketiga dan empat tidak ada kasus baru artritis rematoid definit yang ditemukan. Angka prevalensi artritis rematoid dalam penduduk desa akalah 0.3% (0.2% untuk artritis rematoid definit) dengan rasio sembilan wanita terhadap empat pria.

Artritis erosif radiologik ditemukan pada 0.1% pada pria dan 1.2% pada wanita. Semua kasus adalah positip palsu.

Tes lateks fiksasi ditemukan positip dalam batas 5% dari penduduk, suatu angka yang ditentukan untuk populasi normal. Tes Waaler-Rose hampir positip pada 13% dari penduduk desa ini. Semua titer faktor rematoid yang ditemukan dalam tahap empat ternyata positip palsu. Maksudnya tidak ada asosiasi dengan arthritis rematoid.

Angka prevalensi artritis rematoid yang rendah untuk Indonesia sebanding dengan angka negara berkembang lainnya terutama Afrika. Perbedaannya dengan Afrika adalah rendahnya angka prevalensi artritis erosif radiologik dan tingginya angka tes Waaler-Rose di Indonesia, yang hanya sebanding dengan hasil penelitian di Lesotho. Angka prevalensi Tes Waaler-Rose yang tinggi mungkin sebagai akibat penyakit patek (Framboesia) yang merajalela sebelum dan semasa perang dunia kedua didaerah ini.

Dalam bab ke VII dibicarakan angka prevalensi kelainan tulang belakang. Spondilitis ankilosis tidak ditemukan dalam contoh populasi ini. Spondilosis servikal dan lumbal klinik didapatkan pada 5 dan 4%, agak rendah apabila dibandingkan dengan penduduk kulit putih. Lumbago melebihi empat kali prevalensi dari EPOZ(20% berlawanan dengan 5%), tapi disc prolapse dan sciatica terdapat sama seringnya dengan hasil penelitian di Negeri Belanda (2.3% dan 2.9%).

Nilai sensitivitas, spesifisitas dan prediktip dari abnormalitas waktu pemeriksaan fisik untuk berbagai diagnosa

klinik depersembahkan dalam beberapa tabel. Dengan beberapa kekecualian, hasil penelitian memberi kesan bahwa pada umumnya peneliti menegakkan diagnosa berdasarkan kelainan yang ditemukan waktu melakukan pemeriksaan fisik.

Terdapat suatu perkiraan yang sangat rendah terhadap angka prevalensi osteoartritis klinik lokal dan umum (Bab VIII). Keadaan ini disebabkan oleh bias peneliti karena dari jumlah permintaan akan foto sinar Rontgen lutut berdasarkan indikasi klinik dapat diperkirakan paling sedikit 14% dari penduduk sasaran menderita osteoartritis lutut dan 4.5% mempunyai oateoartrosis radiologik lutut.

Benjolan Heberden dan pembesaran tulang sendi distal interfalang terjadi pada 2.9 dan 2.3% dan ditemukan 1.4 dan 1.9 kali lebih sering pada wanita. Benjolan Heberden lebih sering ditemukan di Liberia dan Nigeria, dan lebih jarang pada penduduk lainnya yang pernah disurvei.

Dengan pengecualian beberapa kelompok sendi, angka prevalensi dalam umur sebanding untuk osteoartrosis radiologik dari tangan dan kaki adalah mirip antara Indonesia dan Negeri Belanda.

Dalam bab IX dipersembahkan angka prevalensi fibrositis bahu (13.9% pada pria dan 14.9% pada wanita) dan epikondilitis (5% pada pria dan 6.1% pada wanita). Fibrositis bahu dan epikondilitis lebih sering terjadi disebelah kanan dari tubuh. Fibrositis bahu lebih sering terdapat pada penduduk Indonesia daripada periartikuler fibrositis pada penduduk EPOZ (3.3 kali lebih sering pada pria dan 2.4 kali lebih sering pada wanita), dengan catatan bahwa kriteria diagnostik pada kelainan bahu adalah berbeda antara kedua penelitian. Demikian juga epikondilitis terjadi 2.5 kali (pria) dan 1.5 kali (wanita) lebih sering pada penduduk Indonesia daripada penduduk Negeri Belanda.

Nyeri tekan terdapat 29% pada pria dan 35.5% pada wanita (3.3 kali lebih sering daripada kejang otot pada pria EPOZ dan 1.9 kali lebih sering daripada kejang otot pada wanita EPOZ).

Kecuali untuk spesifisitas yang tinggi gerakan bahu yang terbatas, asosiasinya dengan fibrositis bahu adalah lemah, tapi nyeri tekan mempunyai nilai sensitivitas, specifitas dan prediktip yang tinggi untuk keadaan ini. Nyeri tekan pada kondil

siku-siku memberi nilai sensitivitas yang sedang (49.3%) sampai tinggi (100%), nilai spesifisitas yang cukup tinggi (79 sampai 98.5%), dan suatu nilai prediktip yang sedang (44.9 sampai 79.6%) untuk diagnosa epikondilitis.

Bab X menguraikan tentang penyakit pirai. Satu kasus presentasi tentang penyakit pirai yang berat, menahun dengan tofi dipersembahkan dalam bab ini. Berdasarkan diagnosa klinik dalam tahap empat angka prevalensi pirai adalah 1.7% pada pria dan 0.05% pada wanita. Tetapi hany 50% dari kasus pirai klinik yang mempunyai hiperurisemia. Apabila hiperurisemia adalah syarat untuk menegakkan diagnosa, maka angka prevalensi pirai menjadi separuh (0.9%). Angka ini tetap lebih tinggi daripada kebanyakan negara berpenduduk kulit putih.

Hiperurisemia terdapat pada 24.3% pada pria dan 11.7% pada wanita. Pada pria angka prevalensi sebanding dengan hasil penelitian di Philipina, Chamorros dari kepulauan Mariana, Kulit Putih dari Selandia Baru, dan Cina Kanada. Diantara kaum Kulit Putih angka prevalensi bervariasi antara 5 dan 30%.

Nilai rata-rata asam urat serum adalah 0.7 mg/100 ml lebih tinggi daripada studi EPOZ baik pada pria maupun wanita. Nilai rata-rata asam urat serum (6.2 mg/100 ml pada pria dan 5.2 mg/100 ml pada wanita) sama dengan orang Philipina yang bertempat tinggal di Philipina, Hawaii dan Alaska. Juga sama dengan orang Melayu, Tamil dan Cina yang menjadi penduduk di Malaysia dan orang Kulit Putih yang bermukim di Selandia Baru.

Karena konsumsi daging dan alkohol adalah rendah sampai tidak berarti di Bandungan, kegemukan tidak ada dan kelas sosial adalah satu, kemungkinan besar hiperurisemia dan penyakit pirai pada penduduk Indonesia ini ditentukan oleh keturunan.

Bab XI menguraikan tentang beraneka ragam kelainan yang ditemukan dalam survei Bandungan. Terdapat satu kasus sistemik lupus eritematosus dan dua kasus sindrom Reiter. Kasus artritis rematoid yang sudah sembuh (burned out) tidak ditemukan karena mortalitas tinggi.

Suatu penemuan yang menarik adalah 2% prevalensi benjolan fibrous bahu pada pria tapi tidak pada wanita, kelainan ini kemungkinan besar sebagai akibat dari memikul barang berat dengan

pikulan.

Osteoporosis yang dinilai secara subjectip dari film, tangan dan kaki terjadi 2 sampai 6 kali lebih sering pada pria dan wanita Indonesia apabila dibandingkan dengan penduduk studi EPOZ. Terutama pada wanita muda osteoporosis ditemukan 18 kali lebih sering pada metakarpal dan 12 kali lebih sering pada metatarsal pada penduduk Bandungan daripada penduduk EPOZ. Pria Indonesia dengan umur sebanding memperlihatkan 3 sampai 4 kali lebih banyak osteoporosis tangan dan kaki daripada pria Belanda. Angka-angka ini memberi kesan bahwa wanita muda kehilangan kalsium berlebihan, mungkin karena menyusui bayi sampai bertahun-tahun.

Pada akhirnya dilaporkan beberapa kelainan radiologik yang ditemukan.

Sebagai penutup **Bab XII** mengadakan penilaian kembali prinsip WHO-ILAR COPCORD dan berdasarkan pengalaman dengan survei Indonesia dibuat rekomendasi untuk survei di hari kemudian. Walaupun dihambat oleh beberapa masalah, COPCORD Indonesia dapat dianggap suatu penelitian epidemiologi yang berhasil dengan kemungkinan kecil adanya bias seleksi. Untuk pertama kalinya angka prevalensi untuk beberapa diagnosa penyakit rematik dalam contoh populasi yang cukup besar dipublikasikan dan dengan biaya yang rendah apabila dibandingkan dengan studi sebanding yang dilaksanakan di negara maju.

Dari penelitian ini ternyata bahwa fasilitas Puskesmas masih perlu menambah perlengkapannya termasuk kehandalan tenaga medik dan paramediknya untuk menangani bermacam-macam jenis penyakit rematik dan masalah pengobatannya. Penataran lebih lanjut masih diperlukan untuk tenaga paramedik dan mediknya terutama karena beban sosio-ekonomik penyakit rematik terhadap masyarakat cukup besar, walaupun lebih kecil daripada penyakit infeksi.

APPENDIX 1

The phase one Philippine questionnaire

Name Head of Household _____

House Number _____ Village _____

NAME	AGE	SEX	OCCUPATION	PAIN FELT AT PRESENT Indicate by Numbers on Diagram	DURATION	INJURY PRESSURE INFECTION COLD	TREATMENT METHOD HERBAL MED. DRUG MASSAGE	BY WHOM HERBALIST MASSEUR SELF DOCTOR	RELIEF OBTAINED YES ____ NO ____

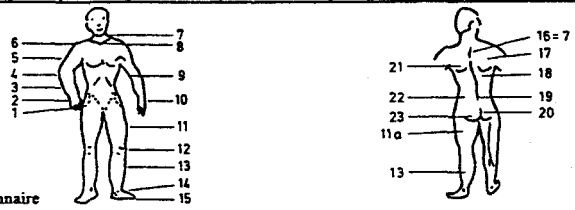
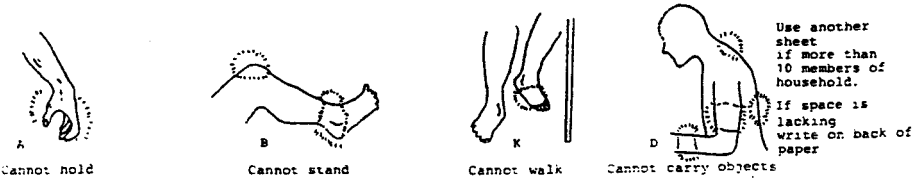


Fig. 1. Phase I questionnaire

NAME	PROBLEM ON MOVING	WHEN DID IT START	POSSIBLE CAUSE	TREATMENT METHOD	TREATMENT BY WHOM	TREATMENT RELIEF OBTAINED YES ___ NO ___	EXAMINATION NUMBER OF ABNORMAL REGIONS	EXAMINATION REGION EXAMPLE SWOLLEN ?



Cannot hold Cannot stand Cannot walk Cannot carry objects

Use another sheet if more than 10 members of household.

If space is lacking write on back of paper

Fig. 2. Phase I questionnaire on degree of disability and treatment

APPENDIX 2

The phase two Bandungan questionnaire

(English version)

First name :
Family :
Single :
Married :
Divorced :
Widow/widower :
Adress :
Occupation :
Age :

Put a ring around the yes and no to show the answer given. If in doubt do not ring either yes or no.

Joints

		Yes	No
1.	Have you ever had pain in the joints of your upper and lower limbs? (Translated into past pain)	1	2
2.	If yes, mark the painful joints in the mannekin		
3.	Have you had pain in the joints in the last two weeks?	1	2
4.	Did you have joint pain for more than six weeks?	1	2
5.	Did you have joint pain following injury?	1	2
6.	If yes, was the injury due to work?	1	2
7.	or transport?	1	2
8.	or sport?	1	2
9.	If the injury recovered did the joint pain relapsed again?	1	2
10.	Did you ever have pain in the big toe?	1	2
11.	Did the big toe swell with the pain?	1	2
12.	Was the big toe red with the pain?	1	2
13.	Had the pain gone in two weeks?	1	2
14 a.	Do your hands, feet and limbs move easily when you get up in the morning?	1	2
14 b.	Do you usually wake up with stiffness/aching in your joints and muscles?	1	2
15 a.	How long does it take for your limbs to loosen up in the morning? hours.....Minutes.....		
15 b.	Does this stiffness or aching in the morning last more than fifteen minutes?	1	2
15 c.	Does this stiffness or aching last till you have:		
	passed water?	1	2
	dressed?	1	2
	had breakfast?	1	2
16.	Is there a grating sound when the joints move?	1	2
17.	Note joints that do not move freely		

.....

Appendix 2 (cont.)

Neck

18.	Have you ever had pain in the neck? (translated into past pain) If no go to question twenty	1 2
19.	Have you had pain in the neck in the last two weeks? If yes mark the mannekin	1 2
20.	Can you bend your neck forwards?	1 2
21.	Can you bend your neck sideways?	1 2
22.	Can you twist your neck?	1 2

Back

23.	Have you ever had pain in the back? (translated into past pain) If yes mark the mannekin. If no go to question 28	1 2
24.	Have you had pain in the back in the last two weeks? (translated into present upper back pain)	1 2
25.	Do you have pain in the lower part of your back?	1 2
26.	Do you also feel this pain in the feet and leg?	1 2
27.	Do you have pain in the middle of your back? If yes mark in the mannekin	1 2
28.	Can you bend your back forwards?	1 2
29.	Can you bend your back sideways?	1 2
30.	Can you twist your back?	1 2
31.	Can you stand straight up?	1 2

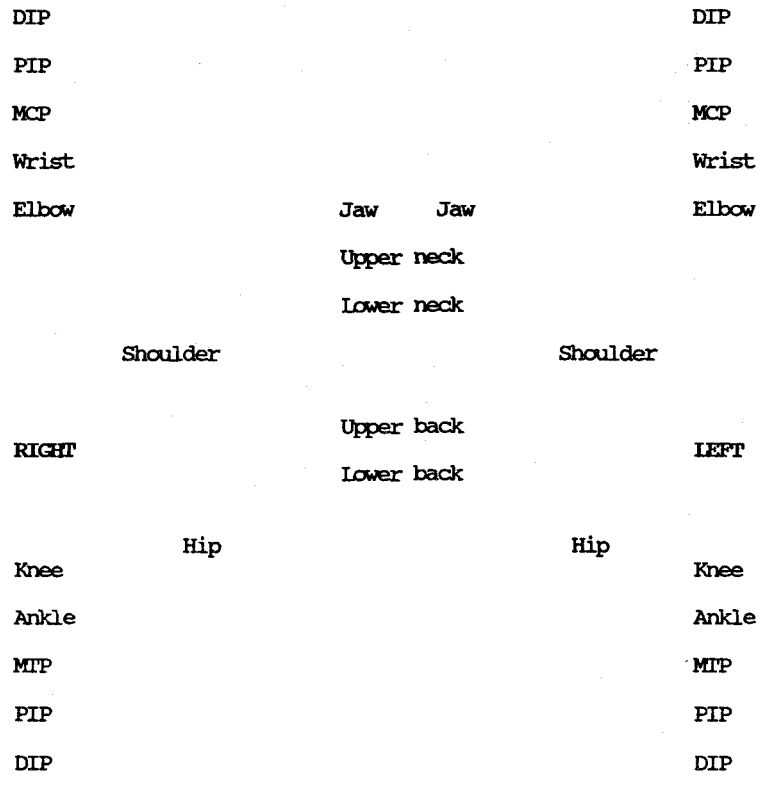
General

Who have you seen with your joint, neck and back pain?

32.	Doctor?	1 2
33.	Nurse?	1 2
34.	Primary health care worker?	1 2
35.	Traditional healer	1 2
36.	Accupuncturist?	1 2
37.	Masseur?	1 2
38.	Selfmedication?	1 2
39.	Herb?	1 2
40.	Have you ever had to stop work because of this? Including house work.	1 2
41.	Can you walk?	1 2
42.	Can you lift things?	1 2
43.	Can you dress yourself?	1 2
44.	Can you carry things?	1 2
45.	Note other findings	
46.	Do you need help for your joint and back pain?	1 2

Appendix 2 (cont.)

Mannekin



APPENDIX 2

The phase two Bandungan questionnaire

(Indonesian version)

Nama panggilan	: First name
Nama keluarga	: Family name
Belum nikah	: Single
Sudah nikah	: Married
Sudah cerai	: Divorced
Janda/Duda	: Widow/Widower
Alamat	: Address
Pekerjaan	: Occupation
Umur	: Age

Berilah lingkaran sekitar angka satu kalau jawaban ya dan sekitar angka dua kalau jawaban tidak.

SENDI-SENDI :

		ya=1	tidak=2
1.	Apakah Sdr. pernah nyeri sendi dilengan dan tungkai?		
2.	Kalau tidak pertanyaan nomor dua dilewatkan. Kalau ya, tunjukkan sendi yang pernah nyeri. Petugas memberi tanda sesuai petunjuk dihalaman 3.		
3.	Apakah Sdr. dalam 2 minggu terakhir ini menderita nyeri sendi?	..	..
4.	Pernahkah Sdr. menderita nyeri sendi lebih dari 6 minggu lamanya?	..	..
5.	Apakah nyeri sendi timbul sesudah kecelakaan? Kalau tidak, pertanyaan no.6,7,8,9 dilewatkan. Kalau ya, apakah kecelakaan disebabkan oleh :	..	..
6.	Pekerjaan = Work	..	..
7.	Transport	..	..
8.	Olah raga = Sport	..	..
9.	Setelah sembuh dari kecelakaan ini, apakah pernah kumat kembali nyeri sendi ini?	..	..
10.	Pernahkah Sdr. nyeri diibu jari kaki? Kalau tidak, pertanyaan no.11,12,13 dilewatkan. Kalau ya,	..	..
11.	Apakah ibu jari kaki selain nyeri juga bengkak?	..	..
12.	Apakah ibu jari kaki merah waktu nyeri?	..	..
13.	Apakah nyeri hilang dalam 2 minggu?	..	..
14.	Pilihlah pertanyaan a atau b, mana yang paling sesuai dengan jawab penderita, yang lainnya dilewatkan.		
	a. Apakah tangan,lengan,kaki dan tungkai mudah digerakkan waktu bangun pagi?	..	..
	b. Apakah bila bangun tidur terasa kaku atau nyeri disendi-sendi dan otot-otot?	..	..

15. Pilihlah pertanyaan a,b atau c, mana yang paling sesuai dengan jawab penderita, yang lainnya dilewatkan :
    a. Berapa waktu yang diperlukan untuk mengendorkan urat2 dan sendi2 ditangan, lengan,kaki dan tungkai pada pagi hari? ..... min ..... jam = hours
    b. Apakah kaku atau nyeri pagi berlangsung lebih lama dari 15 menit ? .. ..
    c. Apakah kaku atau nyeri pagi ini berlangsung sampai saudara :
       -selesai kencing=You've passed water .. ..
       -selesai berpakaian=You've dressed .. ..
       -selesai sarapan=You've had breakfast .. ..
16. Apakah sendi berbunyi waktu digerakkan ? .. ..
17. Catatlah sendi yang tidak dapat bergerak sepenuhnya.

TENGKUK

18. Apakah Sdr. pernah menderita nyeri ditengkuk? .. ..
    Kalau tidak, pertanyaan no.19 dilewatkan.
    Kalau ya,
19. Apakah Sdr. dalam 2 minggu terachir ini menderita nyeri ditengkuk? .. ..
    Berilah tanda digambar pada halaman 3.
20. Dapatkah Sdr.menundukkan kepala ? .. ..
    (sampai dagu menyentuh dada)
21. Dapatkah kepala miring kesamping kanan & kiri? .. ..
22. Dapatkah Sdr.memalingkan kepala kekanan & kiri .. ..

PUNGGUNG :

23. Pernah Sdr.nyeri dipunggung dan atau pinggang? .. ..
    Kalau tidak,pertanyaan no.24,25,26,27 dilewatkan
    Kalau ya,
24. Apakah Sdr. menderita nyeri dipunggung dalam waktu 2 minggu terachir ini ? .. ..
25. Pernahkah Sdr.menderita nyeri dipinggang ? .. ..
    Kalau tidak,pertanyaan no.26 dilewatkan.
26. Menjalarkah nyeri ini sampai ketungkai & kaki? .. ..
27. Apakah nyerinya di-tengah2 punggung/pinggang? .. ..
    Petugas memberi tanda dihalaman 3.
28. Sekarang dapatkah Sdr.membungkukkan badan? .. ..
29. Sekarang dapatkah Sdr. memiringkan badan kesamping kanan & kiri? .. ..
30. Dapatkah Sdr.memutar badan kekanan & kiri sekarang ? .. ..
31. Sekarang dapatkah Sdr. berdiri tegak ? .. ..

UMUM :

Siapakah yang Sdr. mintai tolong, bila nyeri di-sendi2, tengkuk, punggung dan pinggang ?

32. Seorang dokter ? .. ..
33. Seorang perawat atau mantri kesehatan ? .. ..
34. Seorang petugas kesehatan ? .. ..
35. Seorang dukun ? .. ..
36. Seorang ahli tusuk jarum? (accupuncturist) .. ..
37. Seorang tukang pijit ? (masseur) .. ..
38. Mengobati sendiri dengan membeli obat di-warung ? (self-medication) .. ..
39. Minum jamu anti-rematik? (herbs for rheumatism) .. ..
40. Apakah Sdr. pernah tidak dapat bekerja (termasuk pekerjaan rumah tangga) karena menderita nyeri di-sendi, tengkuk, punggung & pinggang? .. ..
(Have you ever had to stop work because of this)
41. Apakah Sdr. dapat berjalan? .. ..
42. Dapatkah Sdr. mengangkat barang? .. ..
43. Dapatkah Sdr. berpakaian sendiri? .. ..
44. Dapatkah Sdr. membawa sesuatu barang? .. ..
45. Hal hal lain yang dapat diketemukan :
46. Apakah Sdr. perlu pengobatan untuk nyeri sendi dan punggung? .. ..

APPENDIX 3

The phase three Bandungan questionnaire

(English version)

Serial District Number 44 <> Serial Number 45 [][][][]

COPCORD PHASE III.

First review the questions asked in the phase II questionnaire and make any corrections needed. Then ask the following additional questions and proceed to the examination sheet.

Name ..... Age .....

46. Religion .....[] 47. Ethnic Group .....[]
48. Occupation..... Code later []
49. For how long? ..... [][] years.
50. Estimate weight of the loads carried in daily work [][] kg
51. Estimate the distance walked daily in work or sport [][] km
(These estimates will be very approximate and will be analysed as high and low only)
52. If work is mainly with hands and arms,1 2 3 describe .....
53. and classify as 1. heavy YES/NO/DON'T KNOW
2. LIGHT YES/NO/DON'T KNOW
3. Repetitive YES/NO/DON'T KNOW
54. How many children do you have?
1. Under 20 years old .....[][]
2. All ages .....[][]
56. Can you read YES/NO
57. Can you write YES/NO
58. What medicine or pills do you take

	Daily doses
1. .....(	)
2. .....(	)
3. .....(	)

EXAMINATION

59. Height ..... cm []
60. Weight ..... kg []
61. Width of knee across condyles [][] [][] cms (use caliper)

GENERAL COMMENTS.

62. Your clinical diagnosis (preferably in English to facilitate analysis).
.....
.....
.....Code later [][]

EXAMINATION SHEET

a. Tendons: either physical signs and symptoms. If none [ ] tick

Column titles 1. Nodules
2. Limitation of movement
3. Swelling of sheets
4. Triggering
5. Pain

	Right					Left				
	1	2	3	4	5	1	2	3	4	5
Flexor wrists	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Extensor wrists	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Finger flexor	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

b. Joints: either physical signs and symptoms. If none [ ] tick

Columns 1. Pain on movement or tenderness
2. Soft tissue swelling or fluid
3. Bony swelling (osteophytes)
4. Bony crepitus
5. Pain
6. Limitation

	Right						Left					
	1	2	3	4	5	6	1	2	3	4	5	6
DIP	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
PIP	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
MCP	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
1st CMC	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Inf. radioulnar	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Wrists	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Elbows	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Shoulders	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Knees	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Hips	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Ankles	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Subtalar/tarsal	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
2nd to 5th. MTP	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
1st. MTP	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
1st. TMT	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Other_____	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Nodules	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

Heberden's nodes grade: ____ (1-4)
Presence of tophi: (circle) ... No; ...Yes
Have these joint signs been present for more than 6 weeks?
...Yes;...No

c. Spine: Either physical signs and symptoms. If none [ ] tick

1. Symmetrical limitation of movement
2. Asymmetrical limitation of movement
3. Deformity
4. Root pain
5. Other pain

	1	2	3	4	5	6	7
Neck	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Dorsal	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Lumbar	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

Describe other pain:

.....
.....
.....
.....

APPENDIX 3

The phase three Bandungan questionnaire

(Indonesian version)

Serial District Number 44 () Serial number 45 ()()()()()

COPCORD Tahap ke III.

Pertama telitilah kembali semua pertanyaan yang sudah dijawab oleh responden dalam kwesioner tahap ke II. Lakukan pembetulan dimana perlu. Kemudian meneruskan pertanyaan2 dibawah ini. Berilah lingkaran pada ya/tidak/tidak tahu, sesuai dengan jawaban responden.

Nama: Umur:

46. Agama () 47. Suku ()
48. Pekerjaan ()
49. Berapa lama bekerja? ()() tahun
50. Kira2 berat beban yang diangkut setiap hari berapa Kg? ()
51. Kira2 berapa jarak yang ditempuh setiap hari dalam pekerjaan atau olah raga? ()() Km.
52. Kalau pekerjaan tangan jelaskan apa.
53. tergolong 1. Berat ya/tidak/tidak tahu
    2. Ringan ya/tidak/tidak tahu
    3. Berulang-ulang ya/tidak/tidak tahu.
54. Saudara mempunyai berapa anak?
    1. Dibawah 20 tahun ()()
    2. Semua umur ()()
56. Saudara dapat membaca? Ya/Tidak
57. Saudara dapat menulis? Ya/Tidak
58. Obat apa yang saudara minum?
    1. dosis setiap hari
    2. dosis setiap hari
    3. dosis setiap hari

PEMERIKSAAN :

59. Tinggi badan ()()() cms
60. Berat badan ()() Kg.
61. Lebar lutut meliputi kedua condyle kanan kiri
    (III) ()() mm
    Diukur dengan meteran kain, 1 Cm diatas garis sendi.

KOMENTAR :

62. Diagnosa klinik saudara :
.....
.....

PEMERIKSAAN MEDIK.

Isilah angka 1 dalam kotak kalau keluhan/tanda ditemukan waktu diperiksa dan angka 2 kalau keluhan/tanda terdapat lebih dari 2 minggu sebelum pemeriksaan. Kalau ragu-ragu isilah angka 3.

a. Tendon :

1.Nodule. 2.Gerakan terbatas. 3.Pembengkakan selaput tendon. 4.Triggering. 5.Nyeri.

	1 2 3 4 5	1 2 3 4 5
Fleksor pergelangan tangan	◇◇◇◇◇	◇◇◇◇◇
Ekstensor pergelangan tangan	◇◇◇◇◇	◇◇◇◇◇
Fleksor jari tangan	◇◇◇◇◇	◇◇◇◇◇

b. Sendi : Kalau tidak ada keluhan/tanda ◇ Tick.

1.Nyeri tekan atau nyeri waktu bergerak.
2.Pembengkakan jaringan lunak atau terdapat cairan.
3.Teraba osteofit.
4.Sendi berbunyi waktu digerakkan.
5.Nyeri
6.Gerakan terbatas.
7.Bunyi sendi waktu digerakkan teraba (palpasi).
8.Bunyi sendi waktu digerakkan terdengar dengan stetoskop.

	Kanan	Kiri
	1 2 3 4 5 6 7 8	1 2 3 4 5 6 7 8
DIP	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
PIP	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
MCP	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
1st CMC	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Inferior radio ulnar	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Wrists	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Elbows	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Shoulder	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Knees	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Hips	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Ankles	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
Subtalar/tarsal	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
2nd to 5th.MTP	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
1st.MTP	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇
1st.TMT	◇◇◇◇◇◇◇◇	◇◇◇◇◇◇◇◇

ain lain keluhan dan tanda :

Heberden's nodes diberi stadium sebagai berikut :

-Kalau terdapat pada satu DIP adalah stadium 1.
-Kalau terdapat pada dua atau lebih DIP adalah stadium 2.
-Stadium 2, akan tetapi dengan keluhan dan gangguan fungsi adalah stadium 3.
-Ada cacat dari dua atau lebih DIP dengan pembengkokan distal phalanx adalah stadium 4.

Heberden's nodes stadium :

Apakah ada tophi : ya/tidak.

Apakah tanda-tanda sendi ini terdapat lebih dari 6 minggu lamanya? Ya/tidak.

Apakah ada Rheumatoid nodules : Ya/tidak.

c. **Tulang belakang** : Kalau tidak ada keluhan/tanda. <> Tick.

1.Gerakan terbatas simetris.
2.Gerakan terbatas tidak simetris.
3.Cacat
4.Nyeri
5.Nyeri akar saraf
6.Lain-lain keluhan dan tanda.

	1	2	3	4	5	6	7
Tengkuk	<>	<>	<>	<>	<>	<>	<>
Punggung	<>	<>	<>	<>	<>	<>	<>
Pinggang	<>	<>	<>	<>	<>	<>	<>

Catatlah lain-lain nyeri.

DIAGNOSA KLINIK :

Jumlah yang sama dengan jumlah responden yang diperiksa atau 10% dari semua responden yang tidak pernah mempunyai keluhan harus diwawancara untuk menjawab pertanyaan dari No.46 sampai dengan pertanyaan No.60 untuk perbandingan.

APPENDIX 4

The phase four Bandungan examination sheets

(English version)

Serial number [ ][ ][ ][ ][ ]

	RIGHT		LEFT	
NECK	no abn []	0 1 2 3 4	[]	0 1 2 3 4
pain on move		[ ][ ]		[ ][ ]
limit rot		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
limit flex		[ ][ ][ ][ ][ ]		
limit ext		[ ][ ][ ][ ][ ]		
limit sideways		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
SHOULDER	no abn	[]		[]
pain on move		[ ][ ]		[ ][ ]
pain sh girdle		[ ][ ]		[ ][ ]
tender spots		[ ][ ]		[ ][ ]
limit elev		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
limit abd		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
limit rot		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
ELBOW	no abn	[]		[]
pain on move		[ ][ ]		[ ][ ]
pain on press med cond		[ ][ ]		[ ][ ]
pain on press lat cond		[ ][ ]		[ ][ ]
soft tissue swell		[ ][ ]		[ ][ ]
limit flex		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
limit ext		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
WRIST	no abn	[]		[]
pain on move		[ ][ ]		[ ][ ]
pain on press		[ ][ ]		[ ][ ]
limit ext		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
limit flex		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
soft tissue swell		[ ][ ]		[ ][ ]
TENOSYNOVITIS		[ ][ ]		[ ][ ]
DUPUYTREN		[ ][ ]		[ ][ ]
CAMPTODACTYLIA		[ ][ ]		[ ][ ]
TENDON NODULES		[ ][ ]		[ ][ ]
MUSCULAR ATROPHY		[ ][ ]		[ ][ ]
ULNAR DEVIATION		[ ][ ]		[ ][ ]

Appendix 4 (cont.)
Phase four Bandungan survey - 2

Serial number [ ][ ][ ][ ][ ]

		RIGHT						LEFT					
CMC-I	no abn	[]	0	1	2	3	4	[]	0	1	2	3	4
	pain on move		[ ][ ]						[ ][ ]				
	pain on press		[ ][ ]						[ ][ ]				
	soft tiss swell		[ ][ ]						[ ][ ]				
	bony enlarg		[ ][ ]						[ ][ ]				
	function limit		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
MCP	no abn	[]						[]					
	pain on move		[ ][ ]						[ ][ ]				
	pain on lat press		[ ][ ]						[ ][ ]				
	soft tiss swell		[ ][ ]						[ ][ ]				
	bony enlarg		[ ][ ]						[ ][ ]				
	limit of movement		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
PIP	no abn	[]						[]					
	pain on move		[ ][ ]						[ ][ ]				
	pain on lat press		[ ][ ]						[ ][ ]				
	soft tiss swell		[ ][ ]						[ ][ ]				
	bony enlarge		[ ][ ]						[ ][ ]				
	limit of movement		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
DIP	no abn	[]						[]					
	pain on move		[ ][ ]						[ ][ ]				
	pain on lat press		[ ][ ]						[ ][ ]				
	soft tiss swell		[ ][ ]						[ ][ ]				
	bony enlargement		[ ][ ]						[ ][ ]				
	limit of movement		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
HEBERDEN NODES			[ ][ ]						[ ][ ]				
VERTICAL TENDERNESS DIP			[ ][ ]						[ ][ ]				
PSORIASIS	no abn	[]						[]					
	elbow		[ ][ ]						[ ][ ]				
	nails		[ ][ ]						[ ][ ]				
SCLERODERMA			[ ][ ]						[ ][ ]				
HIPS	no abn	[]						[]					
	pain on movement		[ ][ ]						[ ][ ]				
	limit of flexion		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
	limit of endorot		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
	limit of exorot		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
	limit of abduction		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
KNEES	no abn	[]						[]					
	pain on movement		[ ][ ]						[ ][ ]				
	pain on pressure		[ ][ ]						[ ][ ]				
	limit of flexion		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
	limit of extension		[ ][ ][ ][ ][ ]						[ ][ ][ ][ ][ ]				
	Baker's cyst		[ ][ ]						[ ][ ]				
	bursitis		[ ][ ]						[ ][ ]				

Appendix 4 (cont.)
Phase four Bandungan survey - 3

Serial number [ ][ ][ ][ ][ ]

		0 1 2 3 4		0 1 2 3 4
ANKLES	no abn	[]	[]	
	Talotibial			
	pain on movement	[ ][ ]		[ ][ ]
	pain on pressure	[ ][ ]		[ ][ ]
	soft tiss swell	[ ][ ]		[ ][ ]
	edema	[ ][ ]		[ ][ ]
	limit dorsal flexion	[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
	limit plantar flexion	[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
	Talocalcaneal			
	limit of supination	[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
	limit of pronation	[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
ACHILLES	no abn	[]	[]	
	swelling	[ ][ ]		[ ][ ]
	pain on pressure	[ ][ ]		[ ][ ]
MTP-I	no abn	[]	[]	
	pain on movement	[ ][ ]		[ ][ ]
	pain on pressure	[ ][ ]		[ ][ ]
	bony enlargement	[ ][ ]		[ ][ ]
	hallux valgus	[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
	limit of movement	[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
MTP-LAT	no abn	[]	[]	
	pain on movement	[ ][ ]		[ ][ ]
	pain on pressure	[ ][ ]		[ ][ ]
	soft tiss swell	[ ][ ]		[ ][ ]
	limit of movement	[ ][ ]		[ ][ ]
	subluxation	[ ][ ]		[ ][ ]
PIP-FEET	no abn	[]	[]	
	soft tiss swell	[ ][ ]		[ ][ ]
	pain on pressure	[ ][ ]		[ ][ ]
	subluxation	[ ][ ]		[ ][ ]
DIP-FEET	no abn	[]	[]	
	swelling	[ ][ ]		[ ][ ]
KNEE JERK		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
ANKLE JERK		[ ][ ][ ][ ][ ]		[ ][ ][ ][ ][ ]
ABN REFLEX		[ ][ ]		[ ][ ]
CVA or POLIO sequelae		[ ][ ]		[ ][ ]
PARALYSIS		[ ][ ]		[ ][ ]
M.PARKINSON		[ ][ ]		[ ][ ]

Appendix 4 (cont.)
Phase four Bandungan survey - 4

Serial number [ ][ ][ ][ ][ ]

0 1 2 3 4

SPINE no abn []
kyphosis [ ][ ][ ][ ][ ]
increased lordosis [ ][ ][ ][ ][ ]
limit of rotation [ ][ ][ ][ ][ ]
limit of anteflexion [ ][ ][ ][ ][ ]
limit of retroflexion [ ][ ][ ][ ][ ]
pain on movement [ ][ ]
tender spots [ ][ ]
pressure pts sciatic nerve [ ][ ]
straight leg raising [ ][ ]

TRAUMA (nature and site)

DIAGNOSTIC CATEGORIES no abn []

	0 1 2 3 4		0 1 2 3 4
Past polyarthritis	[ ][ ][ ][ ][ ]	cerv spondyl	[ ][ ][ ][ ][ ]
rheum. arthritis	[ ][ ][ ][ ][ ]	dors spondyl	[ ][ ][ ][ ][ ]
ankylosing spond	[ ][ ][ ][ ][ ]	lumb spond	[ ][ ][ ][ ][ ]
Reiter	[ ][ ][ ][ ][ ]	lumb DD	[ ][ ][ ][ ][ ]
infect. arthritis	[ ][ ]	disc prolaps	[ ][ ][ ][ ][ ]
gout	[ ][ ]	LOA	[ ][ ][ ][ ][ ]
scleroderma	[ ][ ]	GOA	[ ][ ][ ][ ][ ]
fibrositis should	[ ][ ][ ][ ][ ]	lumbago	[ ][ ]
epicondyl	[ ][ ][ ][ ][ ]	other	
(poly)arthralgia	[ ][ ]	undefined	[ ][ ]

WORKDAYS LOST [ ][ ]
Did you ever have to stop work (incl.housework) because of joint or backpain?

If yes [ ][ ]
How many workdays lost
this year ....days....weeks....months
last year ....days....weeks....months
total workdays lost since onset...days....weeks....months
How do you rate your working capacity at the present time?
same as before the illness []
worse []
better []
Why _____
How do you rate your health at the present time?
worse after onset of illness []
same []
better []
Why? _____

APPENDIX 5

Adjusted phase one questionnaire

(Melbourne version)

Identification Number ☐☐☐☐☐☐

QUESTIONNAIRE FOR A POPULATION SURVEY OF JOINT AND BACK TROUBLE

Sponsored by the World Health Organisation,

The Arthritis Foundation of Victoria and The University of Melbourne.

1. What is your date of birth? day ☐☐ month ☐☐ year ☐☐

   What is your sex? male ☐ female ☐

   What is your postcode? ☐☐☐☐

2. What is your current marital state? (tick the appropriate box)

   never married ☐ currently married ☐ de facto ☐

   widowed ☐ divorced or separated ☐

3. In which country were you born? .....

4. Do you work now? yes ☐ no ☐

   If yes, what is your present occupation? (eg. fitter, secretary)

   .....

   If no, what was your past occupation? (If you have had more than one job, what was the longest job of your working life?)

   .....

   If you are not retired and not working, what is the major reason?

   .....

5. Have you in the last week, had trouble (pain, ache, stiffness)

(a) in the joints of your arms and legs? yes ☐ no ☐

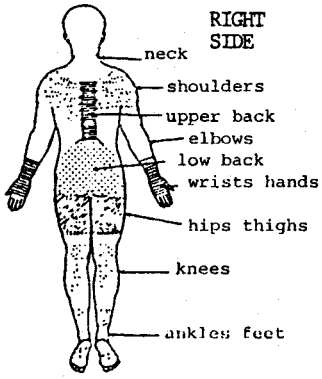
(b) in the neck? yes ☐ no ☐

(c) in the back? yes ☐ no ☐

If no to all of these questions, go to Question 6.

If yes to any of these questions,

please mark on this diagram with a cross where you feel the trouble.



For how long have you had the trouble?

(If you have had trouble in more than one place, choose the longest time).

☐ weeks, or ☐ months, or ☐ years

Go to Question 7 at the top of the next page.

6. If you have had no trouble in the last week,

have you ever had trouble (pain, ache, stiffness) in the past?

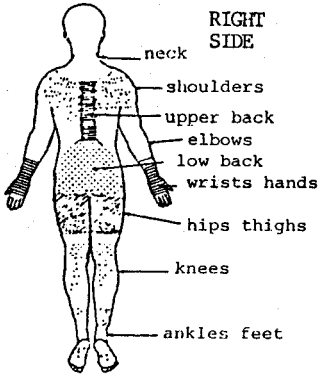
(a) in the joints of your arms or legs? yes ☐ no ☐

(b) in the neck? yes ☐ no ☐

(c) in the back? yes ☐ no ☐

If yes to any of these questions,

please mark on this diagram with a cross where you felt the trouble.



For how long did the trouble last?

(If you have had trouble in more than one place, choose the longest time)

☐ weeks, or ☐ months ☐ years

Please go on to Question 9 on the next page.

7. Do you now have difficulty in performing any of these activities?

(For each activity please tick one box).

	No difficulty	mild difficulty	severe difficulty
standing	☐	☐	☐
walking	☐	☐	☐
lifting	☐	☐	☐
carrying	☐	☐	☐
dressing	☐	☐	☐
bathing	☐	☐	☐
sleeping	☐	☐	☐
using the toilet	☐	☐	☐
working	☐	☐	☐
cooking	☐	☐	☐
shopping	☐	☐	☐
cleaning the house	☐	☐	☐
playing sport	☐	☐	☐

8. If you have trouble (pain, ache, stiffness) now in joints, neck or back are you able to cope with this

very well	☐
rather well	☐
not so well	☐
not at all	☐

9. To obtain help with this trouble (pain, ache, stiffness) have you consulted a doctor? yes ☐ no ☐

10. Have you had treatment for this trouble? yes ☐ no ☐

If yes, from whom? (More than one answer is possible)

general practitioner	☐
chemist	☐
hospital	☐
specialist	☐
physiotherapist	☐
chiropractor	☐
acupuncturist	☐
other:	☐

11. Which of the following treatments were given? (More than one answer is possible)

			Did it help?	
tablets	yes ☐	no ☐	yes ☐	no ☐
injections	yes ☐	no ☐	yes ☐	no ☐
physiotherapy	yes ☐	no ☐	yes ☐	no ☐
surgery	yes ☐	no ☐	yes ☐	no ☐
a special diet	yes ☐	no ☐	yes ☐	no ☐
alternative remedies	yes ☐	no ☐	yes ☐	no ☐
other:	yes ☐	no ☐	yes ☐	no ☐

12. Did you fill in this form yourself? yes ☐ no ☐

If not, who did.....

Are there any comments you would like to make?

.....

.....

.....

Thank you very much for completing this form which will be collected in one week's time.

APPENDIX 5

Adjusted phase two questionnaire

(Melbourne version)

_____

_____

/ /86

MELBOURNE PHASE 2

When we first asked, you indicated that you had joint or back trouble.

1. Do you still have trouble? y/n

   Date last survey: / /86

   If yes,
   Could you tell me where it is (if no: where it was):
   (a) in the joints of your arms and legs? y/n
   (b) in the neck? y/n
   (c) in the back? y/n

2. How would you rate your present joint, neck or back situation?
   excellent y/n
   good y/n
   fair y/n
   not so good y/n
   bad y/n

3. Have you ever had an attack of acute pain in one or more joints (excluding the neck and the back)? y/n

   If yes, in which joints
   shoulders? y/n
   elbows? y/n
   wrists? y/n
   fingers? y/n
   ankles? y/n
   (big) toes? y/n
   other? y/n
   which.....

   If yes,
   Did the pain go in 2 weeks without specific treatment, or in a few days after treatment? y/n

4. Have you ever had more than one attack of acute joint pain? y/n

   If yes,
   Did the pain usually go in 2 weeks without specific treatment or in a few days after treatment? y/n

   If 1.(a):
5. Do (or did) you have pain in the jonts of the hands and/or feet for more than 6 weeks? y/n

   If yes,
6. Have the joints of both hands or of both feet been involved simultaneously? y/n

MELBOURNE PHASE 2

7. Did the joint pain follow strain or injury? y/n
   If yes, which joint?.....

   If 1.(b):
8. Do (or did) you have pain in the neck for more than 6 weeks? y/n

9. Did the neck pain follow strain or injury? y/n

10. Do you have numbness in the fingers of one or both hands? y/n

11. Do you have pins and needles in the fingers of one or both hands? y/n

    If 1.(c):
12. Do (or did) you have pain in the upper back? y/n
    If yes,
    Did the pain in the upper back last for
    (a) more than 6 weeks? y/n
    (b) more than 3 months? y/n

13. Did the pain in the upper back follow strain or injury? y/n

14. Is the pain in the upper back relieved by
    (a) bedrest? y/n
    (b) exercise (moving around)? y/n

15. Do (or did) you have pain in the lower back? y/n
    If yes,
    Did it last for
    (a) more than 6 weeks? y/n
    (b) more than 3 months? y/n

16. Did the pain in the lower back follow strain or injury? y/n

17. Is the pain in the lower back relieved by
    (a) bedrest? y/n
    (b) exercise (moving around)? y/n

18. Do (or did) you also have shooting pain or pain which spreads down the leg and/or foot? y/n
    If yes, which leg or foot? L/R/both

19. Do you feel stiffness of your hands, arms, feet or legs when you get up in the morning? y/n
    If yes, how long does this stiffness take to loosen up?
    (a) less than a quarter of an hour? y/n
    (b) 15 to 30 minutes? y/n
    (c) one to two hours? y/n
    (d) More than 2 hours (eg. whole day)? y/n

20. Do you feel stiffness of your (lower) back when you get up in the morning? y/n
If yes, how long does this stiffness take to loosen up?
(a) less than a quarter of an hour? y/n
(b) 15 to 30 minutes? y/n
(c) one to two hours? y/n
(d) more than 2 hours (eg. whole day)? y/n

Is the stiffness relieved as soon as you move around? y/n

21. Did you go to the doctor for your joint, neck or back trouble? y/n

22. Did the doctor tell you what the diagnosis was? y/n
If yes, I will present you one by one a number of cards with the name of a certain rheumatic condition on it. Please tell me when you recognize the name.
Name condition.....

23. Did the doctor prescribe you medicine? y/n

24. Do you presently use any medicine for your joint or back trouble? y/n
If yes, could I see them?
(Nurse) Please write down names and dosage of all medicines presently taken (including non-rheumatic ones)

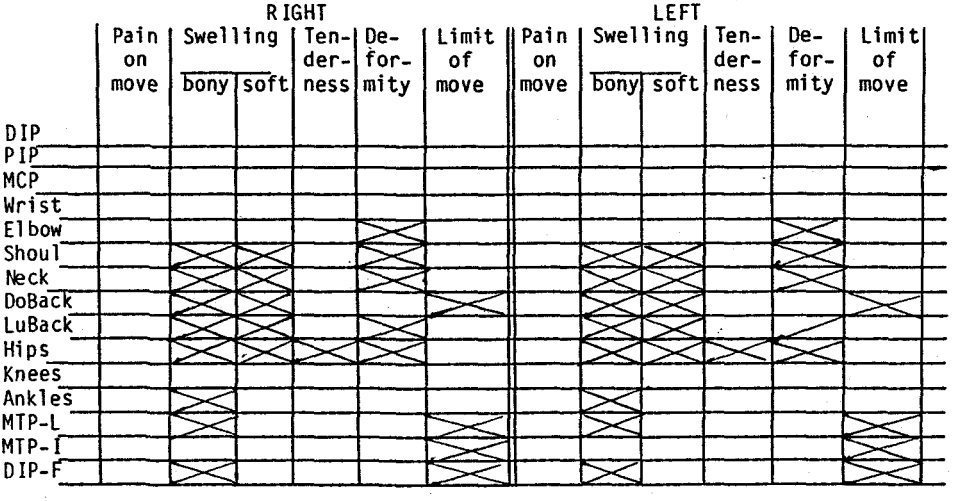
25. How would you rate your present health (not joint) situation?

excellent	y/n
good	y/n
fair	y/n
not so good	y/n
bad	y/n

26. Where in phase 1 present occupation is indicated:
(a) Have you lost work days over the last 12 months? y/n
If yes, how many?.....days
Where in phase 1 no present occupation, and not retired and under 65 years:
(b) Do you not work because of the trouble in your joints, neck or back? y/n
If yes, since how long do you not work any more?
.....weeks
For housewives and people over 65 years
(c) Could you always perform your daily activities over the past 12 months? y/n
If no, how many days could you not perform your regular daily activities? (approximately).....days.

27. If you would allow me, I would like to have a better look at your joints

Examination grid



28. (Nurse) straight leg raising impaired? y/n

29. (Nurse) Do you think any of the peripheral joints are warm in comparison with the other side? y/n
If yes, which joint(s)?.....

30. (Nurse) Do you think any of the peripheral joints are red in comparison with the other side? y/n

If yes, which joint(s)?.....

31. Is there a grating sound (crepitus) when any of your joints move? y/n

If yes, which joint?	Respondent	Nurse
Toes?	y/n	y/n
Knees?	y/n	y/n
Elbows?	y/n	y/n
Wrists?	y/n	y/n
Fingers?	y/n	y/n

When Q.21 answered affirmatively

32. Would you allow us to contact your doctor with regard to your joint or back trouble? y/n
If yes,
Could you give us the name of your
Doctor?.....
Specialist?.....
Hospital?.....

APPENDIX 5

Adjusted phases one and two questionnaires

(Semarang version)

Enter number or tick when the answer is [yes].

ID number [ ][ ][ ][ ]

Hands X-rayed [ ]

Feet X-rayed [ ]

First name :
Family name :
Adress :
Occupation :
For how long : [ ][ ] years
Sex : Male [ ] Female [ ]
Age : [ ][ ] years
Single : [ ]
Married : [ ]
Divorced : [ ]
Widow/widower : [ ]
Can you read? : [ ]
Can you write? : [ ]
How many children do you have under 20 years [ ][ ], all ages [ ][ ]

Question 1 - 27 concern the period starting two weeks ago up to today

	UN	LN	UB	LB	Sacrum	Joint
1. Pain in the last 2 weeks in the	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

If yes tick the locations with pain in the mannekin on page ...
Pain in any joint of the hand (finger joints) and/or feet (toe joints) should be ticked in the box for hand and foot.

Upper and lower neck and back pain should be differentiated.
If there is no pain go directly to question 28.
UN = upper neck, LN = lower neck, UB = upper back, LB = Lower back
Sacrum = sacral area, Joint = peripheral joints

Mannekin

	UN	LN	UB	LB	Sacrum	Joint
2a. Pain follow injury of the	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
2b. Injury due to work in the	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
2c. Injury due to traffic accident	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
3. Pain in the last two weeks in				[ ]		

If yes answer questions 3a, 3b, and 3c.

3a. Lower back pain felt in the leg and foot Right [ ] Left [ ]
3b. Lower back pain felt in the leg Right [ ] Left [ ]
3c. Lower back pain felt in the foot Right [ ] Left [ ]

Adjusted phases one and two questionnaires - 2

ID number [ ][ ][ ][ ]

	UN	LN	UB	LB	Sacrum	Joint
4. Pain lasts for more than 6 weeks	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
5. Can you put your chin on the chest?						[ ]
6. Can you put your ears on your shoulders?						[ ]
7. Turn your head and touch with your chin the shoulders						[ ]
8. Can you reach the floor with your legs straight						[ ]
9. Bend sideways and touch your knees with the fingers						[ ]
10. Can you stand straight up						[ ]
11. Need treatment for pain in the	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
Disability						
12. Stop work because of pain in	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]
13. Can you walk?						[ ]
14. Can you lift things?						[ ]
15. Can you dress yourself						[ ]
16. Can you carry things?						[ ]

17a. Need help from other people for activity of daily living such as toilet, shower, eating, drinking, combing and washing [ ]

17b. Do you need help from other people for household chores? [ ]

17c. If yes, can you get this help? [ ]

What have you done for the pain in your joints and/or neck and/or back? (Utilization of health care facility)

Go to the		Did it help yes	little	no
18. Community health center?	[ ]	[ ]	[ ]	[ ]
19. Doctor?	[ ]	[ ]	[ ]	[ ]
20. Nurse?	[ ]	[ ]	[ ]	[ ]
21. Primary health care worker	[ ]	[ ]	[ ]	[ ]
22. Traditional healer (dukun)	[ ]	[ ]	[ ]	[ ]
23. Acupunturist	[ ]	[ ]	[ ]	[ ]
24. Acupressure	[ ]	[ ]	[ ]	[ ]
25. Masseur	[ ]	[ ]	[ ]	[ ]
26. Take herb	[ ]	[ ]	[ ]	[ ]
27. Buy medicine	[ ]	[ ]	[ ]	[ ]

<u>Past pain means pain of more than two weeks ago and does not include pain mentioned in question one.</u>

	UN	LN	UB	LB	Sacrum	Joint
28. Pain in the past in the	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]

If yes tick the locations of past pain in the mannekin on page ...
Pain in any joint of the hand (finger joints) and/or feet (toe joints) should be ticked in the box for hand and foot.

29. Did the pain in the past last continuously for more than 6 weeks [ ]

	Now	Last 2 wks	Past
30. Did you have pain in the big toe?	[ ]	[ ]	[ ]
31. Did the big toe swell with the pain?	[ ]	[ ]	[ ]
32. Has the colour of the big toe turned red or darkened with the pain?	[ ]	[ ]	[ ]
33. Has the pain gone in two weeks?			[ ]

APPENDIX 6

The adjusted phases 3 and 4 questionnaire and examination sheet

(Semarang version)

Serial number [ ][ ][ ][ ]

1.0 Average weight of loads carried daily in work [ ][ ]kg
1.1 Was the weight carried by means of a resilient wooden pool over the shoulders? [ ]

	weeks	months	years
1.2 For how long	[ ]	[ ]	[ ]
1.3 How many times per	[ ]	[ ]	[ ]

2. Average distance walked daily in work or sport [ ][ ]kms
3. Respondent classifies his/her manual work as heavy [ ] light [ ]
4. Can you do your regular work now? [ ]

	weeks	months	years
If not, how long did you have to stop work	[ ]	[ ]	[ ]

6. Did you have to change jobs in the past because of pain? [ ]
7. If you can do your regular work now, did you have to stop work in the past because of pain? [ ]
8. If yes, how long did you have to stop work in the past uninterruptedly? [ ] [ ] [ ]

	same	worse	better
9. How do you rate your present working capacity?	[ ]	[ ]	[ ]

10. If it is better, why do you feel or think it is better?

	good	average	bad
11. How do you rate your general health now?	[ ]	[ ]	[ ]

Physical examination

4. Height [ ][ ] cm
5. Weight [ ][ ] kg

The rest of the physical examination is the same as Appendix 4 with the exception of the examination of the knees:

	Right					Left				
	0	1	2	3	4	0	1	2	3	4
KNEES no abn	[]					[]				
pain on movement	[ ][ ]					[ ][ ]				
pain on pressure	[ ][ ]					[ ][ ]				
limit of flexion	[ ][ ][ ][ ][ ]					[ ][ ][ ][ ][ ]				
limit of extension	[ ][ ][ ][ ][ ]					[ ][ ][ ][ ][ ]				
Baker's cyst	[ ][ ]					[ ][ ]				
bursitis	[ ][ ]					[ ][ ]				
Swelling	[ ][ ]					[ ][ ]				
soft/fluid	[ ][ ]					[ ][ ]				
bony	[ ][ ]					[ ][ ]				
Bony crepitus	[ ][ ]					[ ][ ]				

APPENDIX 7

Diary of the various phases

7.1 Phase two.

In March 1982 I was approached by Dr.R.D. Wigley whether I would be willing to start a COPCORD survey in Indonesia similar to the one which was underway in the Philippines. Lack of funds, information, expertise, experience and manpower were overcome by raising local funds, and gaining information, experience and expertise through local medical professionals in field surveys. Although previous population surveys in 1977 and 1979 on rheumatic pain in rural areas were disappointing because of very low response rates, the COPCORD phase two interview survey was successfully completed on January 19, 1983, after its official initiation on October 1, 1982.

It was considered better not to use the regular approach of inviting the people to the village hall by the village head as this procedure creates selection bias. The younger people are at school or can not leave their work or employment, while the elderly and particularly those with severe joint pain of the lower extremities can not attend because of the distance. Predominantly those in need of medicine for whatever ailment will then show up and some may even fake symptoms for personal profit. Those who finally do show up are certainly not representative for the target population, while the response rate might be low.

It was therefore decided to do the interviewing by house to house visiting by the primary health care workers. During the weekends on the spot checks were made by the author and his colleagues in order to maintain a high quality. During the survey guidance was received from Dr.K.D. Muirden.

Because at the time it was not foreseen that a follow-up to the phase two survey was going to be executed, the completed phase two questionnaires were sent without identification numbers to both the Department of Epidemiology, Erasmus University Rot-terdam and the Research Laboratories, Palmerston North Hospital, Palmerston North, New Zealand where before data filing they were given an ID number which differed from the ID number later assigned by the author to the original phase two questionnaires.

The first month. The primary health care workers Mr. Ngabdi and Mr. Soehatman were serving the community health center from 7 a.m. to 2 p.m. The daily surveying could therefore only commence after 2 p.m. Depending on weather conditions it started most of the time after 5 p.m. until 9 p.m. and ran full-time on Sundays and Holidays. November to January is in the middle of the rainy season. With only 10% paved roads, the footpaths and dirt roads were rather difficult to travel when they became muddy and slippery after the rains started.

All the completed questionnaires with errors or inaccuracies or those which were incomplete were returned to the primary health care workers for immediate redo and corrections. There were no errors in the proformas of the respondents who never had had musculoskeletal complaints, but after one month survey the error rate was still 1 - 2% in the completed questionnaires of the respondents with joint, neck and back pain.

As the experience of the primary health care workers improved, the weekly returns of completed questionnaires increased. The first week's average was 17 completed questionnaires daily or two questionnaires per hour per primary health care worker. After the fourth week the average was fourty-eight completed questionnaires daily or 6 questionnaires per primary health care worker per hour or ten minutes for one questionnaire. On the average the primary health care workers worked four hours daily for the survey.

The second month. The second month was uneventful, except for the rains pouring down every afternoon and lasting longer and longer. Umbrellas and raincoats were necessary during the weekend checkrounds.

The primary health care workers took their annual two weeks leave and in compensation put in an average of ten hours daily in the field survey with a weekly return of more than eight hundred completed questionnaires. By courtesy of the community health center physician, they were relieved of their duty until completion of the survey.

The third month. Although working full-time, the survey could not be completed until January 19, 1983, because it was not only raining but also storming daily. Particularly the storms delayed the completion of the survey on December 31, 1982, as was originally scheduled.

As invited guest speakers for the First Congress of the Indonesian Rheumatism Association, held in Semarang, July, 1983, Drs H.A. Valkenburg, K.D. Muirden and R.D. Wigley took the opportunity to visit the villages that had been surveyed. It was a great satisfaction to have the whole COPCORD team on site and visit the more severe cases discovered during the phase two COPCORD interview survey. It was encouraging that Dr. Villius Grabauskas, WHO Division of Non-communicable Diseases, in a letter to Dr. Wigley early 1983, said to appreciate being kept informed on the development of the COPCORD population survey in Indonesia, although it was not yet a WHO and IIAR funded study.

7.2 Phase three.

Dr.R.D. Wigley initiated and supervised the COPCORD phase three population survey from October 1 - 12, 1984, on his third visit to the target area. The respondents were daily asked in a group of fifty people to attend the physical examination session at the aid station of the community health center located in the village of Bandungan. Those who did not show up were collected by a rented car. Fourteen subjects who refused this service were examined at home. The phase three interviews and examinations came to an end on December 5, 1984.

The author working full-time was incidentally assisted alternatively by Drs R.B. Wirawan, Soenarto, Soeharyo Hadisapoetro and Hawik Poedjohastoeti S. Photocopies of the completed phase three questionnaires with identical serial number as in phase two were sent to Dr.R.D. Wigley, Medical Research Laboratory, Palmerston North Hospital, New Zealand for analysis. Here they were assigned an ID number which was thought to correspond with the ID number originally given to the phase two proformas by the New Zealand team (see above). In order to identify the correct person proformas from phase three were matched by family and first name, age and sex with the proformas from phase two which had already been numbered. As rural Indonesian people regularly change names and ages are merely guesses within five years, this system did not work out properly. The diskette with the phase three data was sent to Rotterdam, but for obvious reasons turned out not to match with the data on disk from phase two. Consequently this resulted in three datasets with different ID numbers: one phase two file in New Zealand, the same file but with different ID numbers in Rotterdam and a phase three file of which the ID numbers corresponded

with those on the New Zealand phase two file, but the personal data did not. The confusion was maximal. The answer to this sort of embarrassment is never to send the same proformas to different institutions for analysis unless it is clear who got what ID number. But still better the data filing and analysis should be performed in the local situation where the survey has been carried out.

7.3 Phase four.

Enduring hardship should not be an inherent part of population research. It was with this in mind that the subdistrict of Bandungan was chosen for the survey, because it is a weekend resort area with hotel and motel facilities, running water, electricity and an agreeable temperature ranging between 17 - 27 degrees Celsius. The research team was hence decently housed in one of the motels.

As the aid station of the community health center had to function normally and only one waiting and examination room were available, it was decided to rent a three bedroom bungalow unit right besides it. The dining room was turned into an X-ray room with two portable X-ray units, one for the feet and the other for the hands. The kitchen was transformed into a dark room and the living room then became the waiting room. One of the bedrooms was converted into a laboratory and the other two bedrooms functioned as examination rooms. A rented diesel generator generated sufficient power for the X-ray units as the local wiring would not have withstood the current drain.

The first day, Monday, January 6, 1986. This was a hectic day. The organisation of the survey had to be put to action. Problems were popping up where they were least expected. Around one hundred respondents turned up faithfully. As the author was busy running the circus the expatriate epidemiologist had to bear the brunt of physically examining these people and directing and instructing the radiographers who were not familiar with bone radiology. The place was utterly crowded with everybody bumping into each other all the time. Amazingly only fifteen respondents missed their X-ray appointment but several others escaped the bloodcollecting session. Fortunately they could be traced and had their X-ray pictures and blood samples taken the next day.

The improvised research center was situated in the middle of a complex of bungalows. Because of the sound of the diesel generator and the noise the people were creating, it was no wonder that the owner of the bungalow threw us out by 5 o'clock in the afternoon. Having not yet established a routine and everybody exhausted from the first day's confusion, it was a situation that needed quick decisions and fast actions. Fortunately another four bedroom bungalow in a more secluded area could be rented. As the academic members of the survey team also were housed in this motel the likelihood of being expelled was close to zero. Everything was moved over to the new bungalow with everybody working until late that evening. Even a new proforma was designed and typed out, which hopefully would function better than the one used the first day.

The second day. It was sheer luck that in the early morning a local photocopying shop could be found where the new proformas could be multiplied before the examination commenced. The four bedroom bungalow had more space to offer. The diesel generator was installed in the garden. The veranda was used by the primary health care workers to verify the ID number, name, age, sex and address of the respondents who showed up and to attach the phase two proformas to the phase four examination sheets. The large living room served as waiting room before the patients were X-rayed. The dining room was arranged into a laboratory for venapuncture and spinning of the blood. The two X-ray units were housed in the large kitchen with one bathroom turned into a darkroom for film development and another bathroom for film drying.

The weather was cool between 15 and 25 degrees Celsius, and except for the strong winds and rains, a pleasant period was foreseen. In the morning of the second day when everything was running smoothly and things started to settle down in the tide of daily routine, the centrifuge broke down. A call to Semarang, fourty-two kilometers away, brought in a new centrifuge within two hours. Meanwhile the blood samples were stored in an ice box. From this event it became clear that the availability of a car and driver for logistical support was indispensable.

Until the end of the first week things went uneventful as routine had settled in. The average number of respondents seen daily was around seventy. Drs R.B. Wirawan and Soenarto participated in the examination for several hours on alternate mornings.

The second week. In the second week Dr. Valkenburg had to leave for Semarang on alternate mornings to present a two weeks course on basic epidemiology for the senior teaching staff of the Medical Faculty, Diponegoro University, while the author kept the field survey going. One day the freezer which kept the serum frozen stopped running when a tree fell on the power lines during one of those stormy nights. Another smaller diesel generator was rushed in from Salatiga, fourty-five minutes driving away. As the electricity supply was unreliable two diesel generators including two operators/guards were rented for the the rest of the survey period. On the third day of the second week, one of the X-ray electrode tubes burnt out and a new one had to be rushed in from Semarang, the respondents waiting for several hours and being kept happy with food and drinks.

In January it was raining almost every day from morning through night and at times it was storming with heavy gusts of wind. During one of those nightly storms in the second week, a big treebranch with a diameter of twenty cm and about seven meters long fell on the kitchen roof of Dr. Valkenburg's bungalow while he was sleeping peacefully after a day of hard work. It was fortunate that it only crushed the kitchen, otherwise it could have been the end of the survey. Who said epidemiology was not exciting after all? To reduce the hazards for the members of the COPCORD team all the life threatening branches of trees around their bungalows were cut off.

The daily average number of completed proformas dropped down to fifty as after the first week less respondents were willing to come by themselves. From now on almost all the respondents had to be brought in and back home again through the rains and winds by two rented mini-busses. Nevertheless at the end of the second week 720 persons had been examined including radiology and blood sampling.

The third week. The third week was unremarkable, except for the arrival of Dr.K.D. Muirden who arrived at the end of the second week on a clouded, windy and rainy afternoon to enforce the team of examiners.

The daily routine during the six work days of the week comprised of examination of respondents from 8 a.m. to 1 p.m. and from 2 p.m. to 5 p.m. The radiographs collected during the day were evaluated by Dr. Valkenburg the same evening between 8 p.m. and 11 p.m. In the third week he was joined by Dr. Muirden and the author for purposes of observer standardization in reading the films. The full-time research

team followed the daily schedule.

The average daily number of respondents dropped even further when a rumour was afloat in the villages that the blood samples taken were sold abroad for very high prices. It was for the primary health care workers who knew these people for more than thirty years that they could be convinced that this was not true. Nevertheless an excess loss of control respondents occurred.

The fourth week. The last week less than thirty people were seen daily. After some questioning it became apparent that around two hundred farm-hands and vendors declined the pick up service because they would loose one day's earnings by coming to the survey center to spend half a day waiting for their turn to be examined. The farm-hands earned less than and the vendors more than US$ 2.- daily. It was decided to reimburse these people their loss of earnings, but still some fifty respondents refused the pick up service for unknown reasons and they were paid a home visit. The respondents examined at their home were not radiographed but had their blood samples taken and these were kept cool in an icebox for later centrifugation. Several weeks later these people were transported to Semarang for X-ray examination of their hands and feet. The phase four survey was completed in four weeks.

Unfortunately but understandably during the phase four examination twenty-six pairs of serum samples got marked with identical *ID numbers*. This reduced the number of analysable respondents. The last thing to be done was the shipment of the nearly 1000 serum samples to Holland, where for reasons of test comparability and problems with local long term storage management it was thought better to keep the sera in a safeguarded central serum bank. The crate of 28 kg with dry ice and tubes was carried by the author by plane from Semarang to Jakarta International Airport where Dr. Valkenburg was waiting to collect it and transfer it to his own flight to Amsterdam. Regardless many minor and major constraints a three phases COPCORD survey was completed successfully in a rural mountain population in Indonesia.

APPENDIX 8

I. CIOMS (Rome) criteria for active RA (1961)

They consist of the first eight criteria of the ARA.

1. Morning stiffness.

2. Pain motion or tenderness in at least one joint (observed by a physician).

3. Swelling (soft tissue thickening or fluid, not bony overgrowth alone) in at least one joint (observed by a physician).

4. Swelling (observed by a physician) of at least one other joint (any interval free of joint symptoms between the two involvements may not be more than 3 months).

5. Symmetrical joint swelling (observed by a physician) with simultaneous involvement of the same joint on both sides of the body (bilateral involvement of metacarpophalangeal, or metatarsophalangeal joints is acceptable without absolute symmetry). Terminal phalangeal joint involvement will not satisfy this criterion.

6. Subcutaneous nodules (observed by a physician) over bony prominences, on extensor surfaces, or in juxta-articular regions.

7. X-ray changes typical for RA. Degenerative changes do not exclude patients from any group classified as rheumatoid arthritis.

8. Demonstration of rheumatoid factor by any method which, in two laboratories, has been positive in not over 5% of normal controls.

Probable RA = 3 or 4 criteria,
Definite RA = 5 or 6 criteria,
Classical RA = 7 or 8 criteria.

II. CIOMS (Rome) criteria for inactive RA

1. A past history of polyarthritis.

2. Symmetrical deformity of peripheral joints consisting of ankylosis or irreducible subluxation. There must be some involvement of one hand and or foot. Involvement limited to large joints such as the elbows of knees does not satisfy this criterion.

3. X-ray changes of rheumatoid arthritis of grade 2 or more.

4. Positive serological test for rheumatoid factor.

The diagnosis is definite if at least three criteria are fulfilled and probable if two criteria are fulfilled. The modified Rome criteria as they have been used in previous surveys in Africa consist of no. 2, 3 and 4.

APPENDIX 9

I. New York criteria for RA (1966)

1. A history, past or present, of an episode of joint pain involving three or more limb joints but without stipulation as to duration.

2. Involvement by swelling, limitation of movement, subluxation, or ankylosis of at least three limb joints. There must be symmetry of two of the joints involved and there must also be involvement of one hand, wrist or foot. (Excluded are DIPs, the fifth PIPs, the first CMCs, the hips, and the first MTPs. Subluxation of the lateral MTPs must be irreducible.

3. X-ray features of grade 2 or more erosive arthritis in hands, wrists or feet.

4. A positive serological reaction for rheumatoid factor.

There are no suggestions as to the term of definite or probable rheumatoid arthritis fulfilling a certain number of criteria. Exclusions in population studies are not applicable.

II. New York criteria for active polyarthritis (1966)

These are intended for the diagnosis of episodes of polyarthritis. They are derived from the Rome criteria for the diagnosis of active RA.

1. Morning stiffnes of the limbs longer than 15 minutes but not all day.

2. Pain on motion or tenderness in a joint, qualified by excluding the back but including the neck.

3. Swelling in a joint, qualified as soft tissue thickening or effusion but excluding bony overgrowth alone.

4. Swelling in another joint, similarly qualified.

5. Symmetrical joint swelling, similarly qualified excluding DIPs.

Criteria 2 - 5 should be observed by a physician.

APPENDIX 10

ARA criteria for the diagnosis RA (1958)

1. Morning stiffness.

2. Pain on motion or tenderness in at least 1 joint (observed by a physician).

3. Swelling (soft tissue thickening or fluid, not bony overgrowth alone) in at least 1 joint (observed by a physician).

4. Swelling (observed by a physician) of at least 1 other joint (any interval free of joint symptoms between the 2 joint involvements may not be more than 3 months).

5. Symmetrical joint swelling (observed by a physician) with simultaneous involvement of the same joint on both sides of the body (bilateral involvement of proximal interphalangeal, metacarpophalangeal, or metatarsophalangeal joints is acceptable without absolute symmetry). Terminal phalangeal joint involvement will not satisfy this criterion.

6. Subcutaneous nodules (observed by a physician) over bony prominences, on extensor surfaces, or in juxta-articular regions.

7. Roentgenographic changes typical of rheumatoid arthritis (which must include at least bony decalcification localized to or most marked adjacent to the involved joints and not just degenerative changes). Degenerative changes do not exclude patients from any group classified as having rheumatoid arthritis.

8. Positive agglutination test-demonstration of the "rheumatoid factor" by any method which, in 2 laboratories, has been positive in not over 5% of normal controls.

9. Poor mucin precipitate from synovial fluid (with shreds and cloudy solution). An inflammatory synovial effusion with 2,000 or more white cells/mm3, without crystals can be substituted for this criterion.

10. Characteristic histologic changes in synovium with 3 or more of the following: marked villous hypertrophy; proliferation of superficial synovial cells often with palisading; marked infiltration of chronic inflammatory cells (lymphocytes or plasma cells predominating) with tendency to form "lymphoid nodules"; deposition of compact fibrin either on surface or interstitially; foci of necrosis.

11. Characteristic histologic changes in nodules showing granulomatous foci with central zones of cell necrosis, surrounded by a palisade of proliferated mononuclear and chronic inflammatory cell infiltration and peripheral fibrosis.

A. Classical rheumatoid arthritis.
This diagnosis requires 7 or more of the above-mentioned criteria. In criteria 1 through 5 the joint signs or symptoms must be continuous for at least 6 weeks. Any one of the features listed under Exclusions will exclude a patient from this and all other categories.

B. Definite Rheumatoid Arthritis.
This diagnosis requires 5 or 6 of the above criteria. In criteria 1 through 5 the joint signs or symptoms must be continuous for at least 6 weeks.

C. Probable Rheumatoid Arthritis.
This diagnosis requires 3 of the above criteria.In at least one of the criteria 1 through 5 the joint signs or symptoms must be continuous for at least 6 weeks.

D. Possible Rheumatoid Arthritis.
This diagnosis requires 2 of the following criteria and total duration of joint symptoms must be at least 3 months.

1. Morning stiffness.

2. Tenderness or pain on motion (observed by a physician) with history of recurrence or persistence for 3 weeks.

3. History of observation of joint swelling.

4. Subcutaneous nodules (observed by a physician).

5. Elevated sedimentation rate or C reactive protein.

6. Iritis (of dubious value as a criterion except in juvenile arthritis).

E. Exclusions.

1. The typical rash of systemic lupus erythematosus (with butterfly distribution, follicle plugging and areas of atrophy).

2. High concentration of lupus erythematosus cells (4 or more in 2 smears prepared from heparinized blood incubated not over 2 hours), or other clearcut evidence of systemic lupus erythematosus).

3. Histologic evidence of periarteritis nodosa with segmental necrosis of arteries associated with nodular leukocytic infiltration extending perivascularly and tending to include many eosinophils.

4. Weakness of neck, trunk, and pharyngeal muscles or persistent muscle swelling or dermatomyositis.

5. Definite scleroderma (not limited to the fingers). (This is an arguable point).

6. A clinical picture characteristic of rheumatic fever with migratory joint involvement and evidence of endocarditis, especially if accompanied by subcutaneous nodules or erythema marginatum or chorea. (An elevated antistreptolysin titer will not rule out the diagnosis of rheumatoid arthritis).

7. A clinical picture characteristic of gouty arthritis with acute attacks of swelling, redness, and pain in 1 or more joints, especially if relieved by colchicine or accompanied by urate crystals.

8. Tophi.

9. A clinical picture characteristic of acute infectious arthritis of bacterial or viral origin with an acute focus of infection or in close association with a disease of known infectious origin, chills, fever, and an acute joint involvement, usually migratory initially (especially if there are organisms in the joint fluid or response to antibiotic therapy).

10. Tubercle bacilli in the joints or histologic evidence of joint tuberculosis.

11. A clinical picture characteristic of Reiter's syndrome with urethritis and conjunctivitis associated with acute joint involvement, usually migratory initially.

12. A clinical picture characteristic of the shoulder-hand syndrome with unilateral involvement of shoulder and hand, with diffuse swelling of the hand followed by atrophy and contractures.

13. A clinical picture characteristic of hypertrophic osteo-arthropathy with clubbing of fingers and or hypertrophic periostitis along the shafts of the long bones especially if an intrapulmonary lesion (or other appropriate underlying disorder) is present.

14. A clinical picture characteristic of neuro-arthropathy with condensation and destruction of bones of involved joints and with associated neurologic findings.

15. Homogentisic acid in the urine, detectable grossly with alkalinization.

16. Histologic evidence of sarcoid or positive Kveim test.

17. Multiple myeloma as evidenced by marked increase in plasma cells in the bone marrow, or Bence-Jones protein in the urine.

18. Characteristic skin lesions of erythema nodosum.

19. Leukemia or lymphoma with characteristic cells in peripheral blood, bone marrow, or tissues.

20. Agammaglobulinaemia.

It should be noted that these criteria were developed before the new classification of rheumatic diseases adopted by the American Rheumatism Association in 1963, in which ankylosing spondylitis, psoriatic arthritis, and arthritis associated with ulcerative colitis and regional enteritis are listed as distinct from rheumatoid arthritis.

1. Ropes M W, Bennett G A, Caleb S, Jacox R, Jessar R A : 1958 Revision of diagnostic criteria for rheumatoid arthritis. Bull Rheum Dis 1958:9;175-176.

2. Blumberg B, Bunim J J, Calkins E, Pirani C L, Zvaifler N J : ARA nomenclature and classification of arthritis and rheumatism (tentative). Arthritis Rheum 1964:7;93-97.

APPENDIX 11

The 1987 revised criteria for the classification of RA

1. Morning stiffness.
   Morning stiffness in and around the joints, lasting at last 1 hour before maximal improvement.

2. Arthritis of 3 or more joint areas.
   At least 3 joint areas simultaneously have had soft tissue swelling or fluid (not bony overgrowth alone) observed by a physician. The 14 possible areas are right or left PIP, MCP, wrist, elbow, knee, ankle, and MTP joints.

3. Arthritis of hand joints
   At least one area swollen (as defined above) in a wrist, MCP, or PIP joint.

4. Symmetric arthritis.
   Simultaneous involvement of the same joint areas (as defined in 2) on both sides of the body (bilateral involvement of PIPs, MCPs, or MTPs is accepted without absolute symmetry).

5. Rheumatoid nodules.
   Subcutaneous nodules, over bony prominences, or extensor surfaces, or in juxta-articular regions, observed by a physician.

6. Serum rheumatoid factor.
   Demonstration of abnormal amount of serum rheumatoid factor by any method for which the results has been positive in <5% of normal control subjects.

7. Radiographic changes.
   Radiographic changes typical of rheumatoid arthritis on posterior-anterior hand and wrist radiographs, which must include erosions or unequivocal bony decalcification localized in or most marked adjacent to the involved joints (osteo-arthritis changes alone do not qualify).

Rheumatoid arthritis is present if at least 4 of these 7 criteria are fulfilled. Criteria 1 through 4 must have been present for at least 6 weeks.

Patients with 2 clinical diagnoses are not excluded. Designation as classic, definite, or probable rheumatoid arthritis is not to be made.

APPENDIX 12

CIOMS (Rome) criteria for the diagnosis of gout

1. A serum uric acid level above 7.0 mg/100 ml in males and above 6.0 mg/100 ml in females.

2. The presence of tophi.

3. Demonstration of uric acid crystals in synovial fluid or of urate deposition in tissues.

4. A history of attacks of painful joint swelling of abrupt onset with complete clinical remission within a week or two.

The diagnosis is definite if two of the criteria are fulfilled.

APPENDIX 13

New York (1966) criteria for the diagnosis gout

The diagnosis of gout shall be based on either:

(i) the presence of uric acid crystals in synovial fluid or tissue,
(ii) the presence of two or more of the following criteria:

1. A clear history and/or observation of at least two attacks of painful limb joint swelling of abrupt onset, severe pain and complete remission in a week or two.

2. A clear history and/or observation of podagra - an attack as decribed under 1. involving the great toe.

3. The presence of a tophus, observed clinically.

4. A clear history and/or observation of a good respopnse to colchicine, defined as a major reduction in objective signs within 48 hours of the onset of therapy.

The level of serum uric acid is not a criterion.

APPENDIX 14

American Rheumatism Association criteria for the diagnosis of gout

1. Urate crystals in either a joint or a tophus and/or
2. Six of the following twelve criteria
   - 2.1 Maximum inflammation within the first day.
   - 2.2 More than one attack of acute arthritis.
   - 2.3 Monarticular arthritis.
   - 2.4 Redness observed over the joint.
   - 2.5 First metatarsophalangeal joint pain or swelling.
   - 2.6 Unilateral metatarsophalangeal joint attack.
   - 2.7 Unilateral tarsal joint attack.
   - 2.8 Suspected tophus.
   - 2.9 Hyperuricaemia.
   - 2.10 Asymmetrical swelling of a joint on X-ray.
   - 2.11 Subcortical cyst with no erosions on X-ray.
   - 2.12 Negative bacterial culture of joint fluid.

APPENDIX 15

ARA 1982 revised criteria for the classification of SLE

1. Malar rash.
   Fixed erythema, flat or raised, over the malar eminences, tending to spare the nasolabial folds.

2. Discoid rash.
   Erythematous raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions.

2. Photosensitivity.
   Skin rash as a result of unusual reaction to sunlight, by patient's history or physician's observation.

4. Oral ulcers.
   Oral or nasopharyngeal ulceration, usually painless, observed by a physician.

5. Arthritis.
   Non-erosive arthritis involving 2 or more periheral joints, characterized by tenderness, swelling, or effusion.

6. Serositis.
   a) Pleuritis-convincing history of pleuritic pain or rub heard by a physician or evidence of pleural effusion OR
   b) Pericarditis-documented by ECG or rub or evidence of pericardial effusion.

7. Renal disorder.
   a) Persistent proteinuria greater than 0.5 grams per day or greater than 3+ if quantitation not performed OR
   b) Cellular casts-may be red cell, haemaglobin, granular, tubular or mixed.

8. Neurologic disorder.
   a) Seizures-in the absence of offending drugs or known metabolic derangements; e.g. uraemia, keto-acidosis, or electrolyte imbalance OR
   b) Psychosis-in the absence of offending drugs or known metabolic derangements

9. Haematologic disorder.
   a) Haemolytic anemia-with reticulocytosis OR
   b) Leukopenia-less than $4,000/mm^3$ total on 2 or more occasions OR
   c) Lymphopenia-less than $1,500/mm^3$ on 2 or more occasions OR
   d) Thrombocytopenia-less than $100,000/mm^3$ in the absence of offending drugs.

10. Immunologic disorder.
    a) Positive LE cell preparation OR
    b) Anti-DNA: antibody to native DNA in abnormal titer OR
    c) Anti-Sm: presence of antibody to Sm antigen OR
    d) False positive serologic test for syphilis known to be positive for at least 6 months and confirmed by Treponema Pallidum immobilization or fluorescent treponemal antibody absorption test.

11. Antinuclear antibody.
    An abnormal titer of antinuclear antibody by immuno-fluorescence or an equivalent essay at any point in time and in the absence of drugs known to be associated with "drug-induced lupus" syndrome.

Systemic lupus erythematosis is present if any 4 or more of the 11 criteria are present, serially or simultaneously, during any interval of observation.

APPENDIX 16

Classification of functional capacity in RA

Class I: Complete functional capacity with ability to carry on all usual duties without handicap.

Class II: Functional capacity adequate to conduct normal activities despite handicap or discomfort or limited mobility of one or more joints.

Class III: Functional capacity adequate to perform few or none of the duties of usual occupation or of self-care.

Class IV: Total or almost total incapacitation, with patient bedridden, or confined to wheelchair, able to perform little or no self-care.

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Dr. Hans A. Valkenburg, professor of epidemiology at the Erasmus University of Rotterdam, the Netherlands, taught me how to think critically, how to apply scientific methods and the practice of epidemiology. He joined and supervised the phase four COPCORD survey in Bandungan and gave me the opportunity to work in his department in preparing and defending my thesis.

Dr. Kenneth D. Muirden, reader in medicine, Royal Melbourne Hospital, Australia, taught me basic clinical rheumatology and by correspondence led me through the principles of problem conceptualization and study design. His education is still reflected in my daily professional, organisational and amateurish journalistic activities. As the COPCORD coordinator he was also the principle fund raiser for the various studies and participated in the field survey.

Dr. Richard (Dick for his friends) D. Wigley, director of the research laboratory, Palmerston North Hospital, New Zealand, was responsible for the design of the phase two and three studies and the initiator of the latter in Indonesia thereby acting as my first field instructor.

The recommendation of Drs Ray G. Robinson of Sydney, Australia and A.R. Nasution, chairman of the Indonesian Rheumatism Association and head, division of rheumatology, department of medicine, University of Indonesia, Jakarta, Indonesia, made it possible for me to obtain formal clinical education in rheumatology at the Royal Melbourne Hospital. Dr. David Barraclough from the rheumatology unit played a major role

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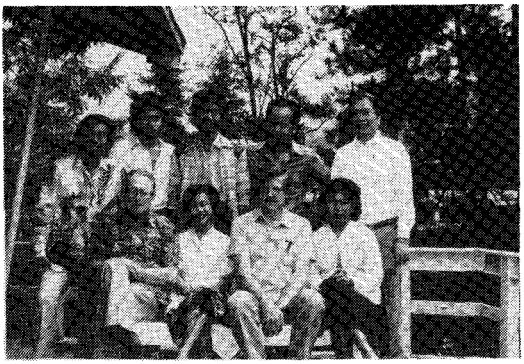

From left to right (standing): Mr.Tukijo Hadi Tanoyo, Samin Widayat, Suyanto, Kalimin, the four assistant radiographers and the author. Sitting: Prof.Hans A.Valkenburg, Mrs. Widawati, midwife, Dr.K.D.Muirden and Mrs.Widati, primary health care worker.

Last but but not least the study at location would not have been possible without the repeated cooperation of the inhabitants and village officials of Bandungan.

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An understanding was reached with Drs Soenarto, R.B. Wirawan and Soeharyo Hadisapoetro that the international publication of the data of the COPCORD study are to be under the the authorship of the author, H.A. Valkenburg, K.D. Muirden and R.D. Wigley, who all four are members of the WHO-ILAR COPCORD Team, and who are responsible for the study design, research funds, execution of the surveys, data management and production of the final scientific report. Due acknowledgments of all local persons involved will be given. The internationally published data are to be at Dr. Soenarto's disposal for local republication.

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Finally, my wife's sacrifices for sharing with me all the anguish of the cultural shock, loneliness and loss of identity in an alien surrounding in my quest for rheumatology training and research should be mentioned. She dutifully and in observance of the oriental customs liberated me from the daily household chores while preparing this thesis and shared the usual sufferings of a promovendus. She is gratefully appreciated.

CURRICULUM VITAE

Johannes Bong Njian Fong was born on October 13, 1935, in Pontianak, West Kalimantan, Indonesia. Due to a clerical error his birth date was registered as October 21, 1935.

He completed the postwar General Primary Dutch School between 1946 and 1951, being four years behind schedule, because all school education was discontinued during the three and a half years of Japanese occupation. He also attended the Dutch Junior High School for two years in Pontianak.

In Jakarta he obtained the Indonesian Junior High School diploma in 1953 and graduated from the Senior High School in 1956. Subsequently he spent one year at the Veterinary Faculty, University of Indonesia in Bogor before moving to the Medical Faculty, Airlangga University Surabaya, where he obtained the medical bachelor's degree in 1963.

In 1964 he was transferred to Solo for three years post graduate compulsory government service at the public health department of the municipality with an after office hours private practice. Besides, he had a part time job at a private hospital with 120 beds.

In 1966 he was transferred to Semarang and was appointed Head of the Medical Service of the headquarters of the Central Java Military Police batallion until 1981 with an after office hour general practice.

In 1968 following the general trend in the community of Chinese origin, his Chinese name was voluntarily altered into Johannes Darmawan in accordance to the 'en vogue' policy for better integration of different ethnic groups in the community.

He was fortunate and honoured to be appointed as Honorary Visiting Associate to spend one year (1980-1981) at the Department of Medicine, the Royal Melbourne Hospital, the University of Melbourne Australia, for clinical rheumatology training with Dr. Kenneth D. Muirden.

Back in Semarang in 1982 he was asked to be the resource person for the Community Oriented Programme for the Control Of Rheumatic Diseases (COPCORD) population surveys in Central Java. He initiated and executed the studies in rural Bandungan described in this thesis and in urban Semarang. Since then he is a

member of the WHO-ILAR (International League Against Rheumatism) COPCORD working group.

In 1983 he started the first and only basic rheumatology out-patient clinic in Central Java with simple laboratory, X-ray and physiotherapy facilities (the Seroja Arthritis Center, Semarang) and was involved in clinical trials of non-steroid anti-inflammatory drugs.

He was elected as first Secretary-General of the Rheumatism Association of ASEAN for the period of 1984 - 1987 (ASEAN comprises of the countries Thailand, Malaysia, Singapore, Brunei Darussalam, The Philippines and Indonesia). Recently he was elected Secretary-General of SEAPAL (South East Asia and Pacific Area League Against Rheumatism) and serves concurrently as (ILAR) Secretary representing SEAPAL for the period 1988 - 1992. He is also appointed Secretary-General for the 7th SEAPAL Congress of Rheumatology to be held in Bali, June 1992.

He is the Editor in Chief of the Indonesian Rheumatism Association Bulletin for 1983 - 1989 and the Rheumatism Association of ASEAN Newsletter for 1984 - 1989, published in Semarang, Indonesia. He is a member of the Editorial Board of the periodical "Advances in Rheumatology", published in New York, U.S.A. He was also recently appointed Corresponding Editor representing ASEAN countries for the EULAR (European League Against Rheumatism) Bulletin, published in Basel, Switzerland.