ADEQUATE HELP FOR PATIENTS WITH CERVICAL CANCER?
THE REFERRAL SYSTEM IN INDONESIA.
A DESCRIPTIVE COMPARISON STUDY IN FOUR PROVINCES

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ABSTRACT

Background: The objectives are the quality of the diagnostic system and the referral for patients with a suspicion of cervical cancer. This research was done in four provinces in Indonesia in the framework of the Community-based Cancer Control Program in Indonesia. Methods: Focus Group Discussions with doctors from the district hospital and Primary Health Care doctors, nurses and midwives as well as interviews with employees from several governmental health departments and a literature study. Results: The referral for patients with a suspicion of cervical cancer works similar in the four provinces. It depends on the facilities available in the district hospital, whether the patient is helped there or referred to the provincial hospital. The facilities available in the district or provincial hospital differ much between the four provinces visited, although they are sufficient to help all patients with (a suspicion of) cervical cancer. Patients are not obliged to follow the referral system. Most cancer patients come to the health care services in a late stage of their disease. A lot of patients drops out to alternative health care. Most of the patients do not have enough money to pay for the treatment. These problems make curative treatment often very difficult. Conclusion: Education about cancer is very important as well as changes in financing of the health care system. Through the education patients are stimulated to seek health care in an earlier stage of their disease and to go to regular health care instead of alternative health care providers.

Keywords: public health care system, chain of diagnosis and treatment, cervical cancer, Indonesia

INTRODUCTION

The Community Based Cancer Control-program (CBCC-program) in Indonesia is developed to make the community aware of cancer. This is done by shifting cancer control from a hospital based model to a community based model. The focus of this program lies on prevention, early detection and early treatment of cancer (Soedoko R et al, 2004). This article focuses on the process after the education from the CBCC-program and especially on the diagnostic process of cervical cancer. The research questions are:

1. Health care system. What is the structure of the health care system in Indonesia with regard to the secondary prevention of cancer, targeted on cervical cancer?
2. If there is a suspicion of cancer diagnosed by symptoms or for cervical cancer by a positive Pap smear test, how does the referral system work?

The research was done in four different provinces of Indonesia; East Java, Yogyakarta, North Sulawesi and Bali.

METHODS

To answer the question about the health care system a search for articles on the internet was done with Google and Pubmed, with the words public health care, health care, public health and Indonesia. One article about cancer control in Indonesia was found (Tjindarbumi D, 2002). To have more information about Indonesia and its health care system one other article was used (Schadé E, Wieringa-de Waard M, Honing C, 2000).

In Indonesia interviews were held with employees of different health departments. To have structured interviews with them questionnaires were developed. In East Java province a clear picture about the health care system in Indonesia was formed and the interviews with the health departments in the other regions were used to test this picture and to see if there exist differences between them.

The main method was Focus Group Discussions. Focus Group Discussions are unstructured interviews with small groups of people, who interact with each other and the group leader. This is to stimulate discussion, gain insights and generate ideas to study a topic in greater depth (Bowling A, 1997). For these discussions was also made use of questionnaires. The participants of the Focus Groups consisted of doctors from the district hospital and doctors, nurses and midwives from the
The health care system

The patient oriented health care system has a similar structure in the four regions in Indonesia visited. When a patient is sick or has certain complaints a Posyandu or small Puskesmas (Puskesmas Induk) is visited, which both function at village level (Soedoko R and Sjahjenny, 2002). The Posyandus are community health care posts that are opened once a week or once a month and are organized by people in the neighborhood together with the health care providers from the Puskesmas, a midwife or a nurse (Soedoko R and Sjahjenny, 2002). A Posyandu has five working programs: immunisation, nutrition, family planning, mother and child care and diarrhea. The Puskesmas Induk has the same functions as a Puskesmas and is run by at least a midwife, a nurse and sometimes a doctor. These small Puskesmas are to assist the bigger Puskesmas. In Java they are necessary to be able to help all the people within one subdistrict. In North Sulawesi they are necessary to overcome the great distances within one subdistrict.

When the Posyandu or the Puskesmas Induk can not provide the proper treatment, the patient is send to the Puskesmas (Soedoko R and Sjahjenny, 2002). These Puskesmas provide primary health care in the subdistricts. The number of Puskesmas differs in every subdistrict and depends on the number of people within that subdistrict and on the size of the subdistrict. The Puskesmas have seven working programs. Six are obliged in every Puskesmas: communicable disease control, environmental health, family planning, health promotion, mother and child care and nutrition. The seventh can be chosen by the Puskesmas according to the needs in the subdistrict. In a Puskesmas work about twenty people, among which a doctor, dentist, sanitation employee, nutrition employee, midwife, nurse, pharmacist, administration employee and medical analyst. During field research it was noticed that the facilities in a Puskesmas are different within every subdistrict. Some are mini-hospitals while others can not even make Pap smears.

If the patient needs further treatment, referral takes place to the hospital that is closest to the home of the patient, usually a type C hospital, which provides secondary health care in the capitals of the districts (Soedoko R and Sjahjenny, 2002). A type C hospital has at least one hundred beds and four specialists; a surgeon, a pediatrician, an internist and an obstetric gynecologist. If more specialist help is necessary, referral to a type B or type A hospital (Soedoko R and Sjahjenny, 2002), which provide tertiary health care, takes place (Soedoko R and Sjahjenny, 2002). Type B hospitals can be found in provincial capitals ( and have minimally three hundred beds and different sub specialists, for example cardiologists and orthopedists, besides the specialists that are also present in the type C hospital (Milton R, 1991). Type A hospitals are in the big cities and are the biggest and most sophisticated in medical staffing and equipment (Milton R, 1991). The conditions for being a type A hospital are disposal of more then seven hundred beds and more specialists and facilities, for example radiotherapy, then in the type B hospitals. In whole Indonesia there are only a few type A hospitals.

The patient oriented health care system in Indonesia provides the community with health care into the villages as described above. In this way everyone who needs medical care can be reached and selection can

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Table 1: Execution of the FGD's

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<thead>
<tr>
<th>Names of the districts</th>
<th>Surabaya</th>
<th>Yogyakarta</th>
<th>North Sulawesi (Manado)</th>
<th>Denpasar</th>
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<td>Surabaya</td>
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<td>Kulonprogo</td>
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<td>Gianyar</td>
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</table>
take place at every level of the health care system. A weakness is that patients are not obliged to follow the referral system. Another problem is that the majority of the inhabitants of Indonesia do not have enough money to pay for the health care that is needed. There does exist a special fund for the less well-off people, but this is not sufficient. Other problems that exist because of the monetary crisis are lack of facilities and manpower.

Many patients go to alternative healers instead of the regular health care. Most people are better known with the alternative healers and have more trust in them then in the regular health care. Besides this, alternative healers are usually cheaper then a Puskesmas or hospital. Ways to prevent patients from going to alternative healers are giving more information about the regular health care and taking care of a health insurance in Indonesia.

Primary and secondary prevention of cervical cancer

The focus in fighting cancer in Indonesia lies at the prevention and early detection. Primary prevention consists of education and health promotion through the use of lectures, slides, posters and leaflets. The education is done by the Puskesmas and the Posyandus in cooperation with the Pembinaan Kesejahteraan Keluarga (Program of Family Welfare, PKK). The PKK is a non-governmental movement that is organized throughout the country and has an extensive teaching program. The idea behind the PKK is to let the community actively participate in developmental activities. To reach this, the PKK uses the governmental structure to reach the community. The chairman of the PKK board is always the wife of the highest local governmental authority. The other board members are local prominent people. On the different levels, PKK-motivators are appointed. Their jobs consist of facilitating, motivating and supervising the PKK activities of the level below. All the members of the PKK, mainly women, do their work on a voluntary base. The PKK invites the employees from the Puskesmas to give education, this means that the Puskesmas goes to the community. The effect of primary prevention is that the community knows about cancer. The parameter through which this can be seen is, in the case of cervical cancer, the number of Pap-smears that are made.

The secondary prevention of cervical cancer consists of making Pap smears. This is done by midwives from the Puskesmas and from the district hospital. The health departments train midwives and doctors from the Puskesmas in making Pap smears. The effect of secondary prevention is early detection of cervical cancer.

Chain of diagnosis and treatment of cervical cancer

A patient with symptoms of cervical cancer visits a Puskesmas most of the time in a late stage of her disease. In the Puskesmas a Pap smear is made when the facilities are available. If not, patients with a suspicion of cervical cancer will be referred to the governmental hospital to make a Pap smear there. In some districts only the gravity of the symptoms can be the reason to refer patients without making a Pap smear first. In the province Yogyakarta in district Gunungkidul a new method of screening for cervical cancer is used since February 2003. This method is called IVA (Visual Inspection by Acidic Acid) and is used for poor patients, because it is much cheaper.

In most of the districts the patient is referred to the obstetric gynaecologist in the district hospital if the Pap smear result is class three or higher. Patients will be referred to a provincial hospital if that hospital is closer to the Puskesmas. In the district hospital further diagnostic procedures are performed. A biopsy is done on patients with a class three or higher Pap smear result. In the province North Sulawesi biopsy on patients with a class three Pap smear result is always done during colposcopy. The district hospital in district Bitung Timur does not have the facilities to perform a colposcopy, so patients with a class three Pap smear result have to be referred to the provincial hospital where colposcopy can be done. The district hospital in province Bali in district Badung can only do clinical staging.

In East Java province facilities for treatment of patients with stage one or two cervical cancer are available in the district hospitals. Patients with higher stages of cervical cancer, who need radiotherapy or palliative care, can only be treated in the provincial hospital. In district Malang facilities for radiotherapy are available in the district hospital. In the province Yogyakarta most district hospitals do not have the facilities to treat patients with cervical cancer. Here the district hospitals only give treatment to improve the general condition of the patients, after which the patient will be referred to the provincial hospital. Only the district hospital in the district Kulonprogo has the facilities to perform surgery, so patients with stage one or two can be treated there. For patients who need chemotherapy or radiotherapy referral to the provincial hospital is inevitable. In the provincial hospital in North Sulawesi, which is a type B hospital, surgery and chemotherapy can be given, but radiotherapy is not available. Patients with stage two B and higher have to be referred to a type A hospital in Jakarta, Surabaya or Makassar. Only women with stage one to two A can be treated in the provincial hospital. In the district Bitung Timur almost all patients do not have
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the money for radiotherapy. Here patients with stage two B or higher are not referred anymore, but only receive palliative treatment from the district hospital. In the province Bali in the district Denpasar surgery and chemotherapy is possible in the district hospital. Patients with stage two B and higher, who need radiotherapy, have to be referred to the provincial hospital. In district Badung only surgery is possible and patients with stage two A and higher are referred to the provincial hospital. In district Gianyar all patients with cervical cancer have to be referred to the provincial hospital.

DISCUSSION

Methods

The main method used for this research was Focus Group Discussions. During these Focus Group Discussions questionnaires with open questions were used to gather as much information as possible. A negative consequence of this is that it is up to the participants of the discussion how much information is given. If something is not mentioned it does not by definition mean that a certain topic does not apply to that district. During the research the questionnaires for the Focus Group Discussions have been adjusted. This was necessary because some of the questions turned out not to be useful, while other questions were necessary to get a better picture of the health care system and of the chain of diagnosis and treatment.

Execution

To make a scientific comparison between the regions visited for the research homogenous Focus Groups are necessary. This turned out to be difficult, especially in the beginning of the project. This is the first reason why Focus Group Discussions can not always be properly compared. The second reason is that not all Focus Groups equally participated. Some Focus Groups were active, while others were passive. Most of the questions that applied for all the participants were answered by doctors. It was difficult to persuade all participants to join actively in the discussion. The reason for this can be found in the strong hierarchy that exists, especially in Yogyakarta. In all four provinces the language barrier gave problems during the collection of the results. It was difficult to fully execute the idea behind Focus Group Discussions. To collect the results for this research subdistricts were visited. A consequence of this is that the collected results not necessarily apply for the whole district. To make sure that the results apply for the whole district, all subdistricts within one district should be visited. This was not possible because of the limited time available.

During some of the Focus Group Discussions contradictory results were gathered. Sometimes the data collected were contradictory to the information gathered from the Focus Group Discussion. To be able to make a quantitative comparison between the provinces visited for this research, data are necessary. In every province visited tables were handed to the supervisor(s) and they were asked to fill in the tables. Almost all data were received, but there were almost no data available about the number of women with symptoms of cervical cancer and the number of referrals so those data are left out of the tables.

CONCLUSION

Patient oriented health care system

The patient oriented health care system has a similar structure in the four provinces in Indonesia that were visited for this project. The first line of health care is provided by the Posyandus and the Puskesmas Induk on village level and by the Puskesmas on subdistrict level. The PKK helps the Posyandus and Puskesmas to reach the community. Secondary health care is given by the type C hospitals that are present on district level. On provincial level the type A and B hospitals give top referral health care. This structure is good, because through the Posyandus, Puskesmas Induk and Puskesmas the whole community can be reached. People who need health care can get help at minimal expenses. Besides that, a selection of patients can be made.

The number of Puskesmas present and the facilities available are very different in every subdistrict. On the higher levels of the patient oriented health care system medical staff and facilities are more extensive and sophisticated. Officially there are conditions that every hospital has to fulfil before it is called a type A, B or C hospital, but in practise those conditions are not always followed (see Table 2).

Chain of diagnosis and treatment

The patient oriented health care system and chain of diagnosis and treatment for patients with a suspicion of cervical cancer work almost the same, because the chain is based on the structure of the patient oriented health care system. The idea behind the chain of diagnosis and treatment seems correct to give adequate help to patients with suspicion of cervical cancer. The build-up and structure of the chain is good. Different facilities are
available on the different levels and referral to the next level is possible in principal (see table 2).

In all provinces the chain of diagnosis and treatment functions similarly. There are a few small differences, which are mostly caused by a difference in facilities available. Within the chain of diagnosis and treatment exists a clear distribution of parts between the different employees from the Puskesmas and the district hospital. Some procedures can be done by different people, but in principal everybody has his or her own task and it is clear what that task is.

The facilities available for diagnostic procedures and treatment in the district hospitals differ much between the four provinces visited. Some district hospitals can only give treatment to improve the general condition of the patient while in others radiotherapy is available. Facilities that are available in a district hospital are sufficient to help all the patients with a suspicion of cervical cancer. If patients have enough money adequate help can be given to them.

In all provinces visited there are two main factors that determine whether a patient is referred to the provincial hospital. Firstly, it depends on the choice and budget of the patient. Besides that it depends on the facilities for diagnosis and treatment available in the district hospital.

If the chain is followed quick diagnosis and quick treatment can take place and a selection of patients who need further help can be made. With the possibility to make Pap smears in the Puskesmas an early selection of patients can be made. It is important to maintain or achieve the possibility of an early selection. Another thing that is very important is follow-up of patients. For this follow-up feedback from the hospitals to the Puskesmas is necessary. In some of the regions visited this feedback is not given properly.

The main problems that undermine the whole system are firstly that patients are not obliged to follow the chain. Secondly many patients in Indonesia do not have enough money to pay for the diagnostic procedures and for the treatment, which makes curative treatment often impossible. The government should help poor patients. At this moment that is almost impossible, because of the monetary crisis in Indonesia and because cancer is not a priority in the health care system. Other problems are that in Indonesia many of the cancer patients come to the regular health care in a late stage of their disease. Besides that some of the patients drop out to alternative healers and return to the regular health care in an even later stage of their disease. Curative treatment is often impossible then.

In almost all provinces there is a regular and good contact between the employees of the Puskesmas and the cadres of the PKK. In some provinces the cooperation is not very strong. In the provinces where the cooperation is strong, the contacts are considered very useful.
### Table 2. Overview

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#### Provincial hospital facilities

| Surgery | + | + | + | + | + | + | + | + | + | + | + | + | + | + |
| Chemotherapy | + | + | + | + | + | + | + | + | + | + | + | + | + | + |
| Radiotherapy | + | + | + | + | + | + | + | + | + | + | + | + | + | + |
| Cooperation between Puskesmas and PKK | + | + | + | + | + | + | + | + | + | + | + | + | + | + |
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