Preventing Cancer across Cultures
Report from a conference in Malmö
on 17th-18th of January 2005
Contents

4  Preface

5  Welcome
   Hans Storm

7  Preventing cancer among ethnic minorities
   Iben Holten

9  Immigrant studies – what can they teach us?
   Anders Ekbom

12 Genes, lifestyle, radiation? Cancer among the Sami
   Eero Pukkala

14 Which issues should be given the highest priority?
   The immigrant point of view
   Mohamed Gelle

16 Which issues should be given the highest priority?
   The immigrant point of view
   Sadia Syed

18 How do we handle the important issues?
   Fahimeh Z. Andersen

20 Which issues are important?
   The ethnic Scandinavian point of view
   Peter Meidahl Petersen

23 How do we handle the important issues?
   Maria Karen Kristiansen

25 Cross-cultural challenges in clinical practice
   Bengt-Erik Ginsburg

28 Interpreters – A sine qua non – an absolute necessity
   Nina Hamerik

30 Interpreting and translating – problems and challenges
   Alma S. Walther
32 Promoting health in a meaningful dialogue
Arild Aambe

35 Ethnic minorities' perception of illness and prevention
Amneh Hawwa

37 Health promotion and prevention in a Danish county
Tom Nauerby

40 Health promotion and the meaning of network in a local Danish community
Inge Wittrup

42 Experiences from the culture-sensitive Reproductive Health Clinic in Malmö
Birgitta Essén

45 International Health Promoters in Malmö
Nabil Rauf og Karin Persson

48 Notes from workshops

52 Presentation of speakers
Preface

Under the heading “Preventing Cancer across Cultures” the Nordic Cancer Society (NCU) held a conference in Malmö 17th-18th of January 2005.

The conference brought together 60 participants representing a wide range of NCU members, health care professionals, practitioners working with ethnic minorities and prevention, authorities and scientists. The participants represented both the Nordic and the “ethnic” point of view.

Reaching ethnic minorities will be an important issue for the Nordic cancer societies in coming years. The aim of the conference was to highlight barriers to communicating health messages and find new ways to involve ethnic minority groups in working with health promotion and prevention. How and through which channels can we reach different groups?

Communication and information were important themes at the conference. Speakers and dialogue in the four workshops highlighted some of the existing problems and barriers to communicating health messages to ethnic minority groups in Scandinavia. Participants also discussed issues related to different ethnic groups’ perception of illness and health, and health professionals with immigrant background were invited to explore this theme.

This report highlights the need to give ethnic minorities the same opportunities and the same treatment in the health care system as the indigenous populations in the Nordic countries. However, this conference has been an important first step in making ethnic minorities target groups for our work with cancer and cancer prevention.

Organizing committee
Iben Holten, Ann-Britt Kvernø (Denmark), Kjell Moe, Ingunn Eck (Norway), Satu Lipponen, Ulla Rautamo (Finland), Thorbjörg Gudmundsdottir (Iceland), Lisen Sylwan (Sweden).
Welcome

Working through the Nordic Cancer Union (NCU) is an elegant way to combine our forces and create synergy, by implementing activities at a Nordic level.

NCU has been operating in Scandinavia since the 1980’s, handling projects within research, prevention, information and patient support. The goal is to improve cancer control for the 25 million people living in the six Nordic countries.

NCU is supporting cancer statistics on a Nordic level, which are comparable, and has funded Nordcan where you can find data about cancer and cancer related deaths in the Nordic countries. The programme can be downloaded for free on the internet from the NCU website. NCU also supports research and has decided mainly to concentrate on epidemiology in the coming years. But NCU will continue working with information and prevention, especially concerning tobacco, physical activity and diet, as well as activities concerning patient support.

It is important for those of you who come from a university setting to know that NCU also takes responsibility for education. For example, the union hosts the Nordic Summer School in cancer epidemiology. It has proved to be a very successful enterprise leading to more research in the Nordic area.

But most important: The Nordic Cancer Union is an advocacy group. We need to exchange experiences and collaborate on both a national and European level, and together we can influence for example The Nordic Council of Ministers and speak with a strong voice in the European setting.

Prevention

The goal of this meeting is to discuss information for ethnic minorities about prevention of cancer – knowledge, symptoms and signs. We know there is a great need for information about health care among these groups, and till now we have not reached them in a satisfactory manner. Immigrants to the Nordic countries are in fact quite similar, as many of them come from the same areas of the world. Therefore it is a brilliant idea to combine forces here.
We need to know how to reach the ethnic groups and understand their culture. We need to know in which ways we can communicate our messages about health promotion and prevention to our new populations. An important goal of the conference is to find out how to produce information materials that can be used in each country. The dialogue with you at this conference is important, and from that dialogue we can all learn to do better in the future.

Preventing cancer among ethnic minorities

“Hee is a better physician that keepes diseases off us, than hee that cures them being on us; prevention is so much better than healing because it saves the labour of being sick”.

Sir Thomas Adams, 1618.

The quote was presented by Iben Holten as ‘the full answer to why we are here’: “Our target group is ethnic minorities, but prevention is our goal,” she said.

Ethnic minorities are different, and there are many different groups, which means different problems and different issues, when dealing with immigrants and prevention. “Therefore it is important that we listen and learn: Which are the subjects we have to address in the future? What do we need to do?” Iben Holten said.

To further this goal, representatives from different ethnic groups have been invited to the conference to present their points of view, because it is important to know what they think, and we need to initiate a dialogue on how we can solve the problems. It is also important to know what people in the Nordic countries regard as problems and how to solve them, and maybe it will be necessary to educate the Nordic people in how to look at different cultures and different people.

The immigrants also need to know that in the Nordic countries there is an obligation to explain to people how the health system is working. "The important part is to do it with respect and to listen to each other", Iben Holten said.

But no prevention without communication. And one part of communication is information, which in itself will not change anything, but it is a prerequisite for working with prevention later on.

Lack of brochures

In prevention you have to work with different sorts of information. But in Denmark, for example, there is a lack of informative material for ethnic minorities, written in their own language. We lack educational materials for language schools and other teaching institutions, and we need to produce informative material that can be used in other contexts, for example for visiting nurses, for meetings in clubs, and for immigrants when visiting the general practitioner.

But first it is necessary to know which subjects are important and to remember that we have to deal with many different ethnic groups, who have different per-
ceptions of illness and health and different understandings of what causes illness. It is therefore important to identify each target group and use different communication strategies.

**One group at a time**

But you can only work with one target group at a time. You have to take into consideration that every group is different and has different needs, and you have to define and particularly address every target group you work with.

Cancer is a growing problem in all groups of people. And if society does not make an effort to prevent the disease, too many people and too many families will suffer, and it will be very costly for the society.

Therefore it is necessary to discuss barriers concerning information both to our own people and to the newcomers to our countries. Information is particularly important when you know that at least 40 percent, maybe even 80 percent, of all cancers are preventable.

There is no excuse for not starting working with prevention in all groups of the population.

**Conclusion**

The aim for this conference is to accelerate the work with prevention within ethnic minorities and find new ways of doing so. That will only be possible if we collaborate and learn how to communicate with the different ethnic groups.
Anders Ekbom

Immigrant studies – what can they teach us?

Anders Ekbom started his speech with an admission: “Prevention of cancer is a subject I have been interested in for quite some time, but I stand here as a symbol of failure, because though we have had access to a lot of data, we have underutilized it to a degree which is almost shameful.”

Traditionally immigrant studies outside the Nordic countries have been a major component in the understanding of different etiological studies, i.e. the cause of illness. The most famous immigrant studies were made in Hawaii in 1980 on immigrants from Japan, and they showed what can be prevented and what will emerge as a problem, when you transplant people from one environment to another.

Sweden has 12 percent immigrants, which is sufficient to gain enough data to teach us where to focus, where we have failed, and where to put the emphasis in preventive measures. It is also important to know how well the health care system is prepared to take care of the social needs of the immigrants.

Anders Ekbom warned that when we speak about immigrant studies one should realize that people who choose to emigrate are a special breed, ‘a healthy sample’. Therefore there is always the danger to infer too much from that population, compared with those who stay at home.

No statistics

Anders Ekbom’s focus was on the major cancers: Cancer of the lung, stomach, colon-rectum, breast and prostate, and a special interest of his: Cancer of the testis, which according to Ekbom, symbolizes how we can use immigrant studies.

Sweden collects data on the cancer occurrence in each county for different age groups etc. However, there are no statistics for different immigrant groups, and to obtain these data you have to challenge two different Swedish authorities, which is also costly. The scarce, existing data is mainly produced by Kari Hemminki’s and Anders Ekbom’s units at Karolinska Institutet.

In order to further pursue the problems with cancer among immigrants, Ekbom pointed out that Swedish Statistics and the Swedish Board of Health should be obliged to publish these numbers on an annual basis, as this will be an important tool for working with immigrants and cancer. Actually the total cancer incidence of male immigrants in Sweden is less than those born in Sweden, but there are differences between different types of cancers.
Since 1985 Sweden has seen a gradual decrease in lung cancer among men. But among women the incidence seems to be growing, and today lung cancer, not breast cancer, is the most common killer of women.

The major cancer killer in Scandinavia was previously cancer of the stomach. But there has been ‘an absolute stunning decrease’ since 1960. The immigrants’ risk of getting stomach cancer is, however, still high especially in certain immigrant groups and it is therefore necessary to educate the GP’s about this problem.

**The biggest killer**

The most common cancer and the biggest killer in Sweden is cancer in colon-rectum. There are no big differences between immigrants and people born in Sweden, probably due to the use of fridges and changed eating habits. But these types of cancers are on the increase among immigrants, especially among immigrants from Eastern Europe.

The prognosis when diagnosed seems to be the same among immigrants and Swedish people, regardless of ethnic background.

Anders Ekbom also talked about the decreased incidence in all ethnic groups with regard to two common cancers, breast and prostate: “Concerning breast cancer it is probably due to two things: That people who emigrate are ‘a healthy sample’, together with an earlier age for the first childbirth and the tendency to have more children than native born Swedes. Both factors decrease the incidence,” he said.

The incidence of cancer of the prostate is higher in Sweden than in most other countries. But immigrants have a decreased risk, regardless of ethnic background and the reason for this remains unknown.

**Enormous potential**

Anders Ekbom said that there is an enormous potential in pursuing studies of different cancers in different immigration groups, but that doctors and scientist have failed doing that. A yearly update on cancer data would be a good start.

One of the most challenging phenomena concerning cancer is the difference in testis cancer incidence between Sweden, Norway, Finland and Denmark. Historically Denmark has had the highest incidence almost worldwide, Finland is lagging behind, Norway is second best, and Sweden is somewhere in between. For Finnish immigrants the decreased risk remained the same regardless of age at immigration or duration of stay.

At present there are statistics on all ethnic groups, and we are currently looking at second generation immigrants. It is very important to know where people are coming from and when, in order to assess the impact of lifestyle changes.
Primary prevention regarding smoking seems to have failed among immigrants in Sweden. Gastric cancer will remain a medical problem among immigrants and has to be explored in the clinical work, especially in immigrants from Asia and Eastern Europe.


3) Kolonel LN.: Cancer patterns of four ethnic groups in Hawaii. Journal of the National Cancer Institute 1980;1127-39
Eero Pukkala,
Genes, lifestyle, radiation? Cancer among the Sami

Finland does not attract many immigrants, but there are ethnic minorities living within its borders. In Northern Finland, the Sami people have lived for centuries as nomads, but times have changed, and now they mainly live from tourism and handicrafts. Eero Pukkala spoke about the Sami people and discussed the roles of their lifestyle, diet, genes, radiation and environmental problems.

Less than 10,000 Sami live in Lapland in an area roughly the size of Denmark. The Finnish population living in the same area has a different genetic background. The nomadic lifestyle of the Sami stopped in the sixties, but when you think about the aetiology of cancer, life habits have some effect on cancer risk.

The diet of the Sami people consists of reindeer and fish, which contain healthy elements, it is, for instance, rich in selenium. On the other hand they have not consumed fruit and vegetables, as they do not grow in Northern Finland.

Air pollution

Their lifestyle comprises certainly not less drinking and smoking than other Finns, and their consumption of fruit and vegetables has been low. The Sami are exposed to air pollution from the Koala peninsula – for instance mercury and cadmium, which has been measured in high amounts in the Sami people. In the 1960’s the Sami were also exposed to a high amount of radiation as a consequence of the nuclear testing in Novaja Semjla and in 1986 the smaller fall-out of the Chernobyl accident. It means that the Sami have a 50 fold internal 137 Cs dose, compared to Finns in the south. There are ongoing studies of Sami in Norway, Sweden and Finland.

The overall age-adjusted cancer incidence among Sami is 40% lower than among Finns on average, while the non-Sami in the area have a cancer risk similar to people in southern Finland. But concerning breast cancer and cancer of the prostate, you see a huge decreased risk. Lung cancer among the Sami is only 10% below the Finnish average, standardised incidence ratio 0.9 – but they smoke a lot.
An exception from the other Sami are the Skolts, who emigrated from Russia after the Second World War. Their cancer risk is slightly higher than for the average Finns. They have a twofold risk of lung cancer and a fourfold risk of stomach cancer as compared to non-Sami. On the Russian side the incidence rates of these cancers are much higher than in Finland, Sweden and Norway. Actually the incidence of stomach cancer among the Skolts in Finland is similar to that on the Russian side and similar to that in Finland 25 years ago.

Cancer mortality among the Sami is 0.6, the same as we saw for the cancer incidence. It suggests that the low risk is not related to low diagnostics – but to something else.

**Conclusion**

Finnish Sami have a substantially decreased cancer incidence, although their life habits are not cancer-healthy. It might be that their diet rich of fish and reindeer-meat has positive effects. Some of the relative risks we have seen are so low that they can hardly ever be explained by external factors, leaving space to genetic factors.

We did not see any effect of ionising radiation in the Sami people. They have a lower than average risk of leukaemia, cancer of the thyroid and breast cancer. This fits with the theory that the human body can adapt some radiation.
Mohammed Gelle

Which issues should be given the highest priority?
The immigrant point of view

Mohammed Gelle has worked for more than ten years with ethnic minorities in Denmark, but this is the first time he encounters the cross section between ethnicity and cancer related issues. He believes that for many ethnic groups cancer is unknown territory and not related to the daily topics of discussion among immigrants. “In my opinion it has to do with the socio-economic background, many people arrive with. Immigrants to the Nordic countries come from countries, where the cancer incidence is not high. Besides there are so many other problems in these areas, which have higher priority than cancer,” Mohammed Gelle said.

When we speak about cancer and the ethnic minorities, one problem is the lack of access to cancer screening. In Denmark, for example, all women are offered screening for cervical cancer. But when ethnic women receive the invitation from the hospital, many just throw it away. There is a lack of awareness about problems related to cancer and cultural problems, and there is no advocacy group providing information about cancer.

“A basic thing would be to inform ethnic minorities in a way that is applicable to them, and which they can understand. It is not enough to mail a letter and expect that they will follow the main stream information channels,” Mohammed Gelle said.

Mobile information unit

Information should be provided to immigrants in their own languages – in print, audio and video. It is also very important to have a ‘mobile information unit’, which can go out with workshops, courses, awareness days and seminars. That is the way many other issues, as forced marriages, aids etc. are dealt with. We can learn a lot from ongoing activities.

It is also very important to change the attitude to cancer among ethnic minorities. That can be done in collaboration with the local ethnic minority-organisations or groups in the field.

“But of course, funding is needed for these activities. Therefore the bottom line is to make it a high priority for the Boards of Health in the Nordic countries to support such initiatives,” Mohammed Gelle said.
Conclusion

To prevent cancer among ethnic minorities we need:

- Education and specific information on cancer designed for ethnic minorities
- Better access and visibility of cancer-screening and -treatment for ethnic minorities
- More research on ethnicity and cancer
- To establish an information strategy for diagnosis and treatment of cancer
- To consider and improve socio-economic factors
- To dispel myths about cancer among minorities
- To change attitudes both among the minorities and health workers
- To give special consideration to the ethnic perspective
- To establish a workable approach in collaboration with ethnic groups
- To raise awareness on cancer and make basic information available in different languages
Sadia Syed

Which issues should be given the highest priority?
The immigrant point of view

Multicultural societies provide many challenges to the traditional way of seeing and doing things, and preventing cancer across cultures is related to information across cultures, including awareness of socio-cultural sensitivities. But there are other barriers than the language. It can be stigma, taboo, gender sensitivities, religion and family traditions. And there are also cultural differences in the way people describe their symptoms, in their expectation of doctors and how they feel about their own responsibility during treatment.

Sadia Syed pointed out that the aim must be to ensure that everyone receives treatment and support. But we know from the Danish health care system that it is not always optimal for the ethnic minorities. We must remember that every patient wants to be treated with humanity and respect and to be seen as the person she is, and not as a representative for a culture or a religion.

Information is very important for both the ethnic minorities and the health staff, and all patients, and their families, should have the same access to information in their own language. But in Denmark there is no information about cancer in the immigrants’ own languages. It might be an idea for the Nordic Cancer Union to develop online information in these languages.

Cultural sensitivities

Cancer research from the UK has shown that the majority of ethnic minorities have little understanding of cancer. There is a big need for information about screening, signs and symptoms of cancer, the importance of seeing a doctor at an early stage, and different treatment options.

But the level of information has to vary. People from small villages have little or no education, while others are well educated. All information must be accurate, easy to understand, in everyday language and observe cultural sensitivities. Audiotapes and videos are helpful.

Sadia Syed told how some immigrants feel they are punished, when they get cancer, some think that it is the will of God and an opportunity to wash out their sins. Some want to go on a pilgrimage, when they are diagnosed with an incurable illness. It is important that the health staff respect the patients’ view.
Generally minority women do not know which kind of help is available and whether they must pay for it. And the perception of health, cultural values, religion and family ethics can be a reason why minority women do not ask questions about treatment and side effects. Thereby it is difficult for them to participate in decision making on health issues.

**Interpreters are important**

Women who do not speak the language of their new country will be marginalized during their contact to the health system. Therefore it is very important to use professional, trained interpreters, educated in health issues and with knowledge about cultural and religious sensitivities. A female interpreter is needed for women with gender related cancers.

It happens that immigrants say they can cope without an interpreter. The reason can be a former bad experience with an interpreter. But there are many disadvantages by not using interpreters, and the treatment can be delayed, increasing the patient's fear and affecting the prognosis.

**Gender differences**

Sadia Syed pointed out the usefulness of arranging seminars in the immigrants' own languages to create awareness, educate about cancer and explain about screening. It can be necessary to arrange seminars for women about gender related cancers, as it is difficult for the women to talk about these matters in the presence of men.

When people emigrate they change lifestyle and dietary habits and need special information with attention to their situation. For instance Hindus and Sikhs are generally vegetarians, and Muslims are forbidden to drink alcohol. However, information on overweight and exercise is important, and seminars for women might be a good idea, as they often do the shopping and the cooking and have the empowerment to change and develop the family's situation.

**Conclusion**

Belonging to a low social class is significant to health, and the socioeconomic differences are important for the cancer-prognosis. It seems that women who belong to low socioeconomic groups are more often diagnosed with cancer in a more advanced stage than women in a higher social class. The vast majority of women from minority groups belong to the low socioeconomic groups and should be targeted as a special group in the Danish national action plan to prevent cancer. Sadia Syed concluded that in order to prevent social inequality the Ministry of Social Affairs ought to take special action concerning minority families.
How do we handle the important issues?

When a doctor meets immigrants as patients, it is important to realize that it is also a meeting of different cultures, and that you have to meet the patient where he or she is. Therefore it is important to have enough time to talk, and that means at least an hour at the first consultation. To illustrate this point Fahimeh Andersen started her speech with a case story, which she said is not unusual:

“A 65-year old Iraqi man, who has had a hard life, came to see me at the hospital. He is diagnosed with cancer of the tonsils. He has smoked 30-40 cigarettes a day for the last 45 years, and does not want to stop: “I have lost my family, everything. The cigarette is my only pal”, he says. He does not want to be treated either: “Your treatment can not do anything worse to me than I have already experienced, and I will die anyway, if God decides it.”

Such a patient obviously presents a challenge to the health care system, and it takes time and work to change his views.

Where do the ethnic minorities in Denmark come from? In the 60’s the immigrants were foreign workers from rural districts in Turkey, Pakistan, Albania and Morocco. In the 70’s came political refugees from Chile, Vietnam and Eastern Europe. In the 80’s they came from Iran, Lebanon, Palestine and Sri Lanka, and in the 90’es followed war refugees from Africa, the former Yugoslavia, Iraq and the Kurds.

The political refugees and immigrants have different backgrounds: National, cultural, religious, social, the level of education, duration of stay, knowledge of the language in the new country and wellbeing.
Dealing with ethnic minorities you work with a pluralistic understanding of illness. This is in contrast to the biological understanding of illness, as we know it in the Nordic countries, that is based on a mechanical understanding of the body. A pluralistic understanding is different and influences the perception of illness, including mental health, sexual dysfunction, handicaps, and childlessness.

There are many cultural taboos and myths. Many patients think that the cause of their illness is a punishment from God, evil eyes, or unbalance (hot/cold). And that it can be treated by prayers and sacrifice, Fatima’s eye, amulets, herbal medicine, biomedicine – and sometimes a mix of it all.

**Nutritional problems**

Fahimeh Andersen argued that communication is a very important element, which should encompass both language, culture and the understanding of different views of illness, and explain about the body and how it functions.

As a doctor she also sees patients with nutritional problems, even malnutrition, caused by different food cultures, and lack of knowledge about healthy food products and how to prepare them. Many immigrants eat too many sweets and desserts and have no energy to stop the children from pestering for sweets, soft drinks and chips, which, furthermore, are regarded as status symbols. The consequences are overweight, diabetes, iron- and vitamin deficiency and bad teeth.

Smoking cessation is also a big problem, and you have to know your patient. Is he illiterate or well educated? Again time is important – you have to use one to one and a half hour at the first consultation to talk about the patient’s background and make a plan.

Finally Fahimeh Andersen talked about the importance of always using an interpreter and not a family member. She has experienced cases, where the family protects the patient and therefore does not tell the patient about his or her cancer illness and its consequences.
Peter Meidahl Petersen

Which issues are important? The ethnic Scandinavian point of view

People from different ethnic groups are as different individually, as Danes are, and as a doctor you never know which kind of consultation it is going to be, before the patient actually is present in the room. Of course there is the language issue, and it is more difficult to get an exact impression of the disease and the symptoms, when you use a translator.

The immigrants’ expectations to the consultation are also different. They tend to expect a solution and a treatment here and now, Peter Meidahl Petersen said, speaking from his clinical experience.

Much of the information on the health status of ethnic minorities comes from studies done in the United States. They show that compared to the white population:

- Ethnic minorities have a higher cancer mortality in the US
- Ethnic minorities have a higher cancer incidence in the US
- Ethnic minorities with the same cancer have a higher mortality in the US

In addition we know that people from ethnic minorities present more advanced stages with regard to breast cancer, prostate cancer and testicular cancer.

<table>
<thead>
<tr>
<th>Table 3.1</th>
<th>Black/White U.S. Cancer Incidence, Mortality, and Survival Rate Ratios</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast (female)</td>
<td>0.98</td>
</tr>
<tr>
<td>Lung</td>
<td>1.27</td>
</tr>
<tr>
<td>Cervix</td>
<td>1.68</td>
</tr>
<tr>
<td>Prostate</td>
<td>1.63</td>
</tr>
<tr>
<td>Esophagus</td>
<td>1.78</td>
</tr>
<tr>
<td>Stomach</td>
<td>1.96</td>
</tr>
<tr>
<td>Liver</td>
<td>1.59</td>
</tr>
<tr>
<td>Colon</td>
<td>1.12</td>
</tr>
<tr>
<td>Oral cavity</td>
<td>1.11</td>
</tr>
</tbody>
</table>


17. januar 2005
We also know that fewer patients from ethnic minorities are included in clinical trials, and several studies show that ethnic minorities and low status people are less likely to participate in screening programmes. For instance concerning mammography, poor women and ethnic minorities use it less than more affluent women and white women.

However, international studies show that it is possible to increase participation in screening programmes among ethnic minorities.

**Equal treatment equal outcome**

Evidence from 6 studies on multiple myeloma and cancers of the cervix, lung, colon and prostate show that people with exactly the same stage of cancer and the same kind of cancer have the same outcome, if they get the same treatment.

But we do see differences, and the explanation lies in a long list of factors:

- Biology, prognostic factors and co-morbidity
- Healthy immigrant effect
- Risk factors and exposures: Tobacco, alcohol, diet and physical activity, environment
- Socio-economic status
- Discrimination
- Knowledge, attitudes and cancer-related behaviours: Delay in seeking diagnosis and treatment, late stage at diagnosis, care related behaviours, such as cancer follow-up, treatment and palliative care, and pain management
- Access to quality care differ
- Low participation in clinical trials
- Culture and language barriers to optimal treatment.

**What we know in Scandinavia**

In a Danish study 3,615 immigrants from different countries were interviewed. It showed that immigrants from non-western countries had:

- A lower risk of cancer
- A lower risk of alcohol related diseases
- Increased risk of heart diseases
- Increased risk of lung diseases
- Increased risk of diabetes
- Reported less exercise
- Reported less tobacco and alcohol

Note: There are variations between different ethnic groups.
Mammography

This study also showed that women from ethnic minority groups had larger tumours when they were diagnosed with breast cancer, compared to Danish women. But ethnic women had a low incidence of breast cancer.

71 percent of Danish-born women accepted mammography. Among the Pakistanis the number was 36 percent, ex-Yugoslavians: 45 percent and Turks: 53 percent. Compliance fell in all ethnic groups with increasing age.

The authors of the study offer the following explanations for the low participation in mammography screening: language barriers, procedure related factors and lower incidence of breast cancer in the countries of origin.

Conclusion

Prevention of a substantial number of cancer deaths among ethnic minorities might be possible, even though the cancer mortality rates seem to be lower, by removing barriers and reducing risk factors. But more knowledge is needed!


Source:
How do we handle the important issues?

There is a fundamental lack of knowledge and research concerning a number of issues, e.g. the prevalence of cancer among different ethnic groups, the prevalence of risk factors and effects of the few existing interventions in primary and secondary prevention. A basic problem is the segregation between majority and minority populations and it is important to take account of the broader contextual issues affecting ethnic minorities in Denmark. In Denmark there is little contact between the different ethnic groups, which leads to a situation where health care professionals sometimes exaggerate the differences instead of the similarities between the Danes and the ethnic minorities.

In trying to prevent diseases in these groups, there are many things to consider:

• Who are the ethnic minorities?
• What are their social circumstances?
• Which issues are important for the target group, seen in the context of their lives?

There are several aspects to consider when preventing diseases among ethnic minorities. When conducting research we must try to involve the target group and not only representatives from different ethnic groups, who might, in fact, not be that representative of the people they are talking on behalf of. It is important to reach the people, we are talking about, and include both men and women in research as well as interventions.

It is also very important to give information back to the people, who have participated in the research, in order to make them feel included. Some ethnic minorities in Denmark have expressed that they feel they are often objects of research and discourses, but not included as subjects, as people who have their own point of view.

Today there are so many different organisations and key persons working in the field, and we need to build a coherent strategy among the organisations and the key persons. It is important to collaborate, and spread out the information we have.

**Participation is the key word**

We all know that health, disease and prevention are related to people's position in society. Therefore intervention from the health care system does not solve all the problems, and we need to work on several aspects in order to promote a better
health status for the ethnic minorities. Some aspects of importance for health promotion and prevention is shared between majority and minority populations, while some aspects (e.g. migration and minority status) are extra dimensions that must be taken into account when designing interventions for ethnic minorities.

We do not know which risk factors are most important to focus on but working on several aspects could be a middle-ground solution. In primary prevention this could be smoking, physical activity, and nutrition, and in secondary prevention we could work on including ethnic minorities in screening programmes. Working with multiple methods and arenas and focusing on involvement is important.

It is also important to bridge the gap between ethnic minorities, the health care system and society in general, thereby creating a society that is more inclusive of these people, and to break down some of the preconceived opinions that are prevalent among both Scandinavian people and ethnic minorities. It is important to move from “how to handle them” to “how to include them”.

Building dialogue through a participatory process and working with key persons and organizations among ethnic minorities is a way forward. By collaborating we can discover which issues are important among specific groups and discover new ways of disseminating information. Working with key persons makes ownership and anchorage of interventions easier and it gives rise to a focus on strengths instead of weaknesses among specific groups. It is possible to make people active and involved. Many second generation immigrants are educated in the field of health sciences, and they have an important perspective to bring to this discussion. It is important to give special attention to the more marginalized ethnic groups and subgroups.

Evaluating the interventions is very important.

Aspects to consider in communication:
• Degree of illiteracy
• Level of knowledge of health and disease
• Attitudes towards health, disease and prevention
• Structural obstacles such as time, financial resources and distance to the intervention
• Imagined obstacles and preconceived opinions among the health care professionals. This makes it important to base interventions on involvement of the target group in planning, implementing and evaluation the intervention.

Communication channels:
Multiple channels: local TV, radio, the internet, migrant magazines, oral dissemination, pamphlets
Multiple arenas: School, the GP, health visitors, organisations
Providing the tools needed (e.g. lessons in nutritional principles, exercise for women)
Bengt-Erik Ginsburg

Cross-cultural challenges in clinical practice

It is very important that cultural issues in health care are not just marginalised as a niche for health encounters with minorities, but to realise that we are all cultural beings, Bengt-Erik Ginsburg said.

“Part of my presentation will reach outwards at the world, and part of it will be looking inwards, into myself, because that is the kind of travelling we are all doing in encounters with people from other countries. We are learning not only about them, we are learning very much about ourselves. And that, I think, is one of the big challenges.”

Three dimensions

Bengt-Erik Ginsburg talked about three dimensions of understanding: Existential, Phenomenological and Biological.

There are always the questions: Why me? Why now? We all carry these questions inside ourselves.

‘Existential’ questions are without answers – you cannot do science on that. The big question is the meaning of life. The existential dimension of man is man as a person and of human integrity. ‘Phenomenological’ is rational, about man as an actor, about culture, human autonomy, about illness. ‘Biological’ is the medical,
man as an organism, nature, disease, origin of people, ethnicity as some kind of biological idea of origin.

It is good to have these three dimensions in mind when it comes to human encounters, and all of us, who work in health care, should carry them with us. The so called popular traditions have very much to do with the phenomenological and existential values, while the professional modernity is mainly concerned with the biological aspect.

On one hand we have tradition, and on the other well tried experience. We are very traditional in the health care profession, and that is not easy to change. Looking upon culture we have to take migration into consideration, because migration is a transition. You carry your luggage of experiences with you, but that is exposed to forces demanding change. And you will change, so you are not the same.

Here you have the dynamics of cultural traditions: On one side the nostalgia, on the other side the forces of integration. What comes out, is a balance between the two. That is how life is for everyone.

Intercultural encounters can be symmetric or asymmetric. By a symmetric encounter I mean that from the stranger’s point of view you are also a stranger, and that is a good thing.

But asymmetric encounters are at a higher risk, because maybe you are not aware that you have a stranger in front of you. But he may look upon you as a stranger. That may happen when Swedish patients meet Swedish doctors. Sometimes the big differences are visible to you and you realize that you have to build bridges to cover the gap, but the small differences may be invisible, and you do not even try to build a bridge.
Culture conflicts and ethics

In the Western value system we put the individual in focus. You can see this in all the human rights conventions and United Nations' declarations about equality. This is a conflict, because when you work with minorities as groups, the ethnic minority group interest may conflict with the individual member of the group, for instance the women, young women in particular.

The Western common value system has a corresponding value system in medical care with the individual patient in focus, informed consent, confidentiality, autonomy and integrity. All these keywords are related to the single person.

Bengt-Erik Ginsburg concluded his speech by talking about the cure and the care – stressing how important it is to give the patient the power of life back after the doctor’s cure.
Nina Hamerik,  
**Interpreters – A sine qua non – an absolute necessity**

Nina Hamerik began by stating that interpreting can be very exhausting because four things are going on almost simultaneously: You listen to what one of the parties is saying, you try to understand, you analyse the message and you translate it into the other language.

At the same time you listen to yourself, because otherwise you are not able to correct yourself. Because we all make mistakes.

Nina Hamerik has been training interpreters who work for refugees and immigrants in Denmark for many years. She ran her first training programme for interpreters in 1982, the second in 1985 and the third from 1988 to 1990. They were all closed down because of lack of funding.

In 1996, Denmark got a new professional training programme, the so-called state-certified interpreters’ programme. This is a programme under the Open University. The programme is rather expensive for the students.

In 2000, the programme was cut down from 400 to 200 lessons, and subjects such as knowledge of the Danish society and professional ethics were cut out. Since 2002, no new students have applied for admittance. This is not so very surprising. If you have to pay a high fee to attend classes and if, at the same time, there are no formal requirements for qualifications when you want to work as an interpreter for refugees and immigrants, as is the case in Denmark, why bother?

Knowledge of the Danish society and principles concerning ethics and confidentiality are extremely important to an interpreter, especially in small immigrant communities where the interpreter, the family and everybody else know each other. In case confidentiality is not respected, suddenly everybody knows all the problems of a certain family. From her own personal experience Nina Hamerik knows that many families prefer a Danish interpreter so that they can be sure that nobody is going to gossip.

Nina Hamerik stated that many users do not have sufficient knowledge of how to use interpreters, to what extent and why this is important, and used the following two examples to illustrate her point:
A couple of days ago I was called to one of the big hospitals in Copenhagen. The patient was a man from Algeria. He had been a patient for a long time and had not had an interpreter. The staff had tried to speak English to him, which he did not understand. Sometimes a friend who spoke a bit of Danish translated. Finally they called an interpreter. It then turned out that the patient who had been treated at the hospital for six months did not even know he was suffering from gangrene.

On that same day I worked for a patient from Burundi in the psychiatric ward of the same hospital. The patient, I was told, had been hearing voices for a very long time. He had not had an interpreter either, but instead the ward had used his brother. The patient had complained about his treatment, and there was a hearing. During his stay in hospital, he had not even understood how to take his medication. Therefore he had had ups and downs and very bad periods, when he began to hear voices again.

“We need qualified interpreters who can translate correctly and know the terminology, and it is also important that we know how to use them”, Nina Hamerik concluded.

“There is much work to be done in this area. First of all we have to agree that interpreters must be trained and that we all have to understand how to use interpreters. In that way problems concerning understanding and confidentiality can be reduced considerably”.

NCU Conference report
Preventing Cancer across Cultures

Nina Hamerik,
Interpreters – A sine qua non – an absolute necessity
Alma S. Walther

Interpreting and translating – problems and challenges

Most foreign interpreters are not only interpreters, but also cultural intermediaries, who on daily basis try to help their countrymen and Danes to understand each other, in spite of the differences in traditions, religions and opinions on life in general.

Good language skills are obviously very important, but interpreters must also have a decent knowledge of many other aspects in society, or a specific knowledge in certain areas. Furthermore, a great deal of empathy is needed.

When interpreting, the hard and the exciting parts are about finding out what sort of language is used by a client. My judgement has to be quick. Speaking in an academic language to someone, who has barely got four years of school or is even illiterate, would not be adequate and appropriate. Still, there is a thrill and a challenge in interpreting for those, whose vocabulary is poor.

No supervision

Foreign interpreters are often caught in battles against prejudice and ignorance. Our main task is to get a right message across, leaving no space for misunderstandings, which could lead to a dangerous outcome (for instance in hospitals and in the law courts).

Foreign interpreters in Denmark have practically never had any supervision. That makes interpreting a very hard work, especially when dealing with victims of torture, violence and rape.

Foreign interpreters in Denmark are also often criticized for not having a proper education. The truth is that many interpreters would willingly take a degree but so far, that has been impossible to do in Denmark.

In 2004, The Business School in Aarhus offered a training programme for interpreters, but they could not attain scholarships, as other students in Denmark can. Furthermore, they were supposed to pay 5000 Danish crowns per semester, which they could not afford.

The sad fact is that there are no regulations in Denmark within this area, and everybody can call her- or himself an ‘interpreter’. The only demand that appears from time to time is that an interpreter must not have a criminal record.
When children translate

Authorities in Denmark, especially hospitals, are mainly concerned about the interpreter’s fee and in order to save money, they allow children and other relatives to function as interpreters for their parents and family members. This is not only wrong professionally, but also very wrong morally.

For example, when hospitals let children translate for their parents, who are diagnosed with cancer, children often choose not to tell their parents about their cancer diagnosis.

They are free to do so, because they can say whatever they like and leave out whatever they want to, no one checks it anyway.

The parents are left in complete ignorance and are deprived of the right to know what they can expect and how much time they have left.

The children do so because they think it is for the best. Although the cancer patients who accidentally found out that they had been lied to about their diagnosis, were very sad and angry. They would have wanted to know; to be able to travel to their home country, while there still was a time, to say goodbye to those they left behind. I have witnessed this many times, too many.

I do not think that the hospitals are aware of this, but I do not think that they care much about this issue anyway. If they did, they would have made sure that children and relatives would not have a chance to do the interpreting.
Arild Aambø,
Promoting health in a meaningful dialogue

“Primærmedicinsk Verksted” - the workshop on primary health care – was created in Oslo in 1994 in order to involve immigrants in empowering and capacity building activities in a way that would create social support and social networks. The workshop is situated in the old part of Oslo, on the ‘other side of the railroad tracks’, where people do not have access to good health care services.

The aim was to improve and promote health in a multicultural society and the key words: Involvement, empowerment, information, social support and networking and how to create a socioeconomic upwards mobilisation. These are not isolated issues. They will have to fit together.

When we started this project we wanted to create a centre that could somehow elicit resources from the immigrant societies, to support natural health and to articulate pain and needs in their own community. We wanted to encourage them to show their strength and coping skills, and to challenge them so that they could make their own decisions – many of them were not used to that. We wanted to train them to become group leaders, maybe to run their own projects. It was very ambitious.

**Solution focus therapy**

We started to teach the participants a model for therapy called ‘solution focus therapy’, that works from ‘a not knowing’ position. We work through asking questions, and the issue is which kind of questions it is wise to ask, and the therapy creates a space for the immigrants so that they can come forward with their own views.

We also needed to create status around this work. As you know, people who work with marginalised people have a tendency to become marginalised themselves. To counteract this we had to join forces with different institutions and international contacts.

**Basic thoughts about culture**

The anthropologist E.T. Hall said: “Culture hides more than it reveals and what it hides, it hides most efficiently from the members of the culture.”

We have to be very careful not to expect people to be able to reveal their own culture. They simply come as individuals. And when people say: ’My culture does
not allow this’, it is not about the culture, it is about communication breaking down.

Another concern: We are working with prevention, giving a lot of advice about what people should do or not do. But advice does not fit very well with empowerment, and one of the issues was how we could somehow integrate the idea of prevention with empowerment.

We found that if it is collaborative, provides resources and facilities to free self-corrected capacities, if it avoids the one-down position of many help-for-help relationships, and if we are sensitive to the culture and the traditions – then maybe it will work.

Did it by the book

When we started we did everything by the book: Written invitations, phone calls the day before, coffee and cakes for the meeting and interpreters in five languages. And when the meeting started there was only me, my co-worker and five interpreters. Later people started to come. After one hour we were nine or ten people, four had been invited and some had heard about the meeting from other sources. Out of this we managed to start some kind of collaboration.

The question that really made a difference was when I, as a medical doctor, whom people knew, asked: Are you willing to help us? Up till then they had challenged me in every way like “Have you lost your licence? What are you doing here? Are you going to do a Ph.D. on us?”

But this question really made a difference, and they were more than willing to help, because they were suffering.

Integration happened

We decided on asking the women to do a cooking course for health professionals so they could learn a bit about the different cultures and which kind of food the immigrants eat. They had never done anything like that before – they were illiterate people, who came out of their kitchens. They knew how to cook, but had no idea how to teach, and it took half a year to prepare them. But then, to my surprise, the course was a big success and had to be repeated 26 times.

It gave the women increased self esteem of course, but it also made them want to learn to speak Norwegian. The training for teaching created a lot of questions, and they became very curious about what the Norwegians were thinking about this and that. The women came out of their isolation, and now that they could meet people on equal terms, integration happened. Many got jobs.
The most interesting thing for me as a doctor was that the women came and said to me that they wanted to run groups for other women, who did not speak Norwegian, did not go out and had no access to information about the Norwegian society. It was very touching to me that they had picked up my model.

After two weeks they had established 15 groups, and they arranged themselves 230 group meetings.

We learned that people want to be convinced that improvement is not threatening to their basic, personal values. The women said they had risen in their own self esteem, and that they had become more independent. They felt fulfilled because they were doing something worthwhile, because they were doing something they had never thought was possible in their family.
Amneh Hawwa

Ethnic minorities' perception of illness and prevention

Immigrants in Scandinavia have one thing in common: They are all different. But still there are some general characteristics of how people from the third world perceive illness and health.

When meeting and treating immigrants as a doctor it is important to remember that they arrive with a pluralistic view of illness and another perception of the body and how it functions, than is common in the Western world. Not only of the physical health, but also of mental illness, sexual dysfunction and childlessness.

Besides you should know how the health care system in their country is organized, and how they use it.

In the Western model we believe that the body is a machine, and if you are ill, it is a kind of dysfunction of the machine. Therefore we have a highly specialised health sector which we believe in.

Among the older generation of immigrants cancer is regarded as the most horrible illness and as a sign of punishment from God, the evil eye, evil spirits, or imbalance between hot and cold.

Educated people now know different – intellectually, that is. But the feeling about cancer is so horrible in some groups that it makes a kind of black out, just talking about it or talking about preventing cancer. So they shut down.

You can seek treatment in the official health sector, but many people in the Middle East and Africa still use the family, the folklore, a person with a special position in the society or the imam.

Taboos and myths

There are other cultural barriers. I once saw an Arabic woman, who said she had a terrible monster in her stomach. Some doctors would think she was a psychiatric patient – but in fact she suffered from too much stomach acid.

We also have to know about taboos and myths, when we talk to people from ethnic minorities, because we stand a better chance of reaching them and talk about prevention.
We know that chronic disease which ends in suffering and death is a very big taboo and normally you would be afraid talking of it. So if you love your mother, your father, your husband, you do not tell them the truth, because they will become very sad and loose their hope. Therefore when you tell Arabic, Turkish or Pakistani immigrants that they have cancer, they will say ‘please do not tell my mother, do not tell my husband’.

But as a doctor you cannot comply, as we live in a country where documentation is very important, and there are rules for the relations between you and the patient. This is one of the big problems in the communication – the family wants something, the patient wants something and the doctors want something. But they do not want the same. Therefore it is very important to develop a form of communication which leaves all three parts satisfied.

Now in the Middle East there is a big interest in the European model of prevention, and people are happy to receive this information, especially the educated, the young people and the modern people.

**Body contact is taboo**

Ethnic minorities are interested in screenings and checks. But when it comes to gynaecology there are special considerations. I always explain my patients that the point of the examination is that they can be sure if they have cancer of the cervix or not. When you examine them you will touch them of course, and for some women, especially the married women, body contact is taboo.

Islam says that ‘help is more important than the rule’ but not all women take religion into consideration in that moment and become very upset. From they were very small they have been taught that the body is taboo. Therefore you have to use a lot of time to show them respect, make them relax and make them comfortable, before you start a gynaecological examination.

We have to use a different sort of information to make these women understand that screening is an important tool for prevention. To tell that screening is for all women in a certain age group regardless of nationality, and that they are not targeted because they are a special group that have more disease than others.
Tom Nauerby

Health promotion and prevention in a Danish county

Tom Nauerby presented some preliminary findings from a research project about the health behaviour of Iraqi refugees in the Danish town, Esbjerg. The project is carried out in collaboration with Lisbet Vestergaard Hansen, health visitor in Esbjerg, and Anette Reinhold, senior lecturer at the nursing school in Esbjerg. The project began in the autumn 2003 and the research is still in progress.

The project has three goals:
1. To draw a picture of the general lifestyle of Iraqis living in Esbjerg regarding illness and health behaviour
2. To find an explanation of their behaviour and health priorities on the basis of their cultural background and social situation.
3. To develop a model for health promotion and prevention to be used by nurses and other health professionals working with ethnic minorities.

The data was collected by group interviews with Iraqis and interviews with Danish general practitioners. Then followed personal interviews with Iraqis and finally a survey based on a questionnaire designed from themes from the interviews. The Iraqis were chosen as a target group, mainly because it is the second largest of the ethnic groups in Esbjerg, consisting of refugees who have come to Denmark within the last ten years. This relatively short time-span gives us a better opportunity to study the actual process of cultural contact. But the focus on the Iraqis also had its drawbacks. Many of them were suspicious as to why they were the focus of attention and felt singled out in a negative way.

In this presentation we will focus on three themes:
• Compliance in relation to lifestyle changes
• ‘Action competence’
• The notion of risk

Professional tunnel vision

Many Danish health professionals complain about poor compliance among ethnic minorities, especially concerning lifestyle changes and health promotion. They blame the minorities’ culture, where ‘culture’ gets the status of a black box, when something goes wrong in the dialogue.
But when we take a closer look at this and try to include the perspective of the Iraqis themselves, it becomes clear that non-compliance encompasses very different situations. Usually you talk of non-compliance, when the patient does not follow the prescribed treatment. But in the following I will talk about non-compliance in relation to advice and recommendations on lifestyle changes, given by a health professional. In this context it does not necessarily mean that the patient does nothing. But the problem is that when the patient actually does take action, it often passes unnoticed, because it does not count in the professional perspective.

The health professional has a clear idea of what the patient ought to do. But if the patient does not follow the instruction, it is regarded as yet another case of non-compliance. This we have coined ‘professional tunnel vision’.

An important source of non-compliance is the Iraqis rather low expectations to Danish health professionals especially general practitioners. Iraqis usually have higher expectations of Arabic doctors in their homeland or in Syria. They are used to pay for this kind of service and to get something in return in the form of medicine. The more they pay, the better a doctor they get. But this is not the case in Denmark, and as a consequence some Iraqis feel they are being cut off with fine words instead of treatment.

The concept of lifestyles

In the national strategy for public health in Denmark in the period 2002-2010 special attention is paid to the so-called ‘lifestyle illnesses’ such as cardiovascular diseases, diabetes and cancer.

The focus is directed towards risk factors embedded in people’s everyday life and therefore not easy to change overnight. The relation between exposure and illness is not obvious, as it develops over a very long period of time, if at all. And when we look at the distinction between deterministic and voluntary factors, we are clearly dealing with the latter.

In a deterministic conception people are exposed to external threats such as pollution and holes in the ozone layer, on which the single individual only has a limited influence. Life style factors, as smoking and exercise, are clearly so-called voluntary factors that the single individual chooses more or less freely.

This is one of the key issues when dealing with the Iraqis. It is clear that they have a different conception of the single individual’s competence to benefit health and avert illness.

Diseases, as our informants often explained, are in the hands of God. He decides who become ill and who is lucky enough to stay healthy. It also became clear that their focus of attention was directed to more immediate threats in the environ-
ment, like tainted foods, infections and nuclear radiation from uranium bomb fragments left over from the wars.

**The crux of the matter**

It is important to note that there is an important common denominator: Whether we are talking about fate or dangers to the health from tainted foods or radiation, they are external factors, not easily influenced by the single individual. As we see it, this is the crux of the matter.

It is, however, only one side of the coin. The other has to do with the Iraqis’ notion of danger and risk in relation to health and illness.

Risk is fostered by choice and decision, while danger is something beyond our control, according to the German sociologist Niclas Luhmann. When we are talking about health promotion and lifestyle changes among ethnic minorities, our perspective is usually on risk and the single individual’s ability to take action, while the Iraqis’ focus of attention is on dangers to their health on which they have very little influence.

Our results indicate that the root of the problem lies in an unhappy combination of lacking action competence, and a focus on dangers in the external world, whereas health professionals are usually preoccupied with risks rooted in our lifestyle.
Inge Wittrup,

Health promotion and the meaning of network in a local Danish community

“Networking integrates people, because you can influence their health behaviour, and because the participants, in a way, are under a sort of social control. The other part of networking is that you have an expectation that people might help you if you get sick or your social circumstances deteriorate”, Inge Wittrup said.

Inge Wittrup told about a project about health promotion and the meaning of networking that took place in 2003 in Bispehaven, an ‘immigrant ghetto’ in Aarhus. The project was made in collaboration with a social worker and the aim was to find out how networks can be created in the context of health, social integration and social support. Bispehaven is situated in the western part of Aarhus, where a large group of ethnic minorities with both health problems and social problems lives. The target group was women from different ethnic minorities – Kurds, Somalis, Iraqis and Turks.

The headline was ‘Social inequality in health, especially in groups that lack networks’ and we worked with other social workers to establish the network. It also demanded partnership between our group, the county and the municipality of Aarhus, the housing area, private organisations and of course the women themselves.

The women had “flex jobs”, worked for the housing area, or cooked for children in kindergarten, but they were all caught by the same problem: They saw their doctors all the time and went to the social security services to say, that they were unable to work, because of different sorts of pain. They had complex diagnoses without really having a diagnosis, which would bring them further along in the system. Therefore many of these women expressed that it was impossible for them to engage in society in a full scale.

Formalized meetings

We wanted to encourage ‘acting competence’ in the women to make them think about how to get out of the doctor’s waiting room and the social security services.

The duration of the meetings was 3-4 hours, and we kept them formalized: The same place, the same room, the same rituals. The women started by telling what had happened since the last meeting, and whether some of the issues from last
time had changed, and if they had had successes in their lives. The participation rate was 76 percent.

We offered the women a space to share their personal problems and made them realize that other women in the same situation had the same health-problems. And we encouraged the women to find the solutions themselves.

In the beginning we discussed whether interpreters were necessary. But we decided to try to do without, because some of the women spoke a little Danish, and during the three months we spent in the network, more than half of the women were able to communicate in Danish, because we created the space for it.

Lifestyle was discussed a lot in the group, and we invited doctors and physiotherapists and did gymnastics with the women. In that way we brought in the issues of physical activity and nutrition, and during that process the women in fact found physical activity important.

We found that concerning the issue of physical activity the women are caught between several different roles, which they are supposed to have in the family and in the Danish Society. It is very difficult for them to engage in activities, even if we create the opportunities for them to be together.

Health workers and social workers have to step in and assist in creating these networks, because it helps the women to get a bit further in their lives, and to go back to their families and tell how important it is for them to do physical activities together. It will be interesting to see if it works when the authorities draw back. Because the idea is that the women should take over the networks themselves and establish more networks.

**Conclusion**

Creating networks is a valid health promotion strategy among immigrant women, which also helps their integration. This kind of networking could make a change both in the way we approach this kind of work and in the way the groups could engage in health promoting activities themselves.
Birgitta Essén

Experiences from the culture-sensitive Reproductive Health Clinic in Malmö

“In Malmö every fourth person is foreign born and in our obstetric ward every third woman giving birth is foreign born. Six to seven years ago the health care providers were very irritated and had a lot of ideas and thoughts about how foreign born women should act or deliver, and everybody were very sure about the differences between Swedish and foreign women giving birth”, Birgitta Essén said.

Birgitta Essén started researching this problem in the first epidemiological study of its kind: “Are foreign born women and their infants at increased obstetric risk in Sweden?”

She stressed that research means to find new knowledge and ask yourself if the old knowledge is all right in a new setting, in a new population.

She has worked together with the anthropologist Sarah Johnsdotter, and they found that some new social and cultural factors were actually related to perinatal mortality. They also found examples that show that migration has changed tradition, maybe in a positive way but also in a negative way.

The study shows that being a foreign born woman is not a big problem in Sweden, unless you are from Africa’s Horn. There is a majority of women from Africa’s Horn and Somalia. The study shows that they have a four fold increased risk for perinatal mortality, even after adjusting for well known biological and social risk factors.

“But even if they had higher risk of dying during delivery, they did not have a higher chance to come to the intensive care unit. That gave us the idea that the reason might be sub-optimal care. There could be social and cultural factors that are not well known in Sweden, which might have an impact on perinatal mortality”, Birgitta Essén said.

Fear of caesarean section

Birgitta Essén and Sarah Johnsdotter interviewed the women about giving birth in Somalia and in Sweden, and were told about the fear of caesarian section, and also about the women’s wish to have small babies, because “a small baby is a small problem”.

NCU Conference report
Preventing Cancer across Cultures
Birgitta Essén
Experiences from the culture-sensitive Reproductive Health Clinic in Malmö
It was obvious that there had been some sort of miscommunication or misunderstanding, while the women were in the obstetric ward. That was tested in a further study, which showed that during seven years one baby had died in Sweden because of some sort of miscommunication. They had not used an interpreter.

The researchers also found that quite a large group of women had been involved in some sort of misunderstanding. Interpreters were used, but they could see that the doctor or the midwife was living in his or her own world, and that the patient had a totally different conception of what was going on.

For instance in Sweden during pregnancy there is a big focus on foetal growth, and everybody in Sweden knows that if you have a small baby you do ultrasound. But when the pregnant Somali women were told that their babies were small, they thought it was great. Therefore they did not come to the controls, and this poses a very serious problem. Because sometimes there is a pathological problem with the placenta, which means a higher risk of perinatal mortality.

Another thing: In Sweden all women want a caesarian section. But the Somali women have a logical reason to be afraid, because their experience from Somalia is that it is very dangerous.

A caesarian is decided in five minutes, but the women did not want to talk about it, and they refused it. We have very sad stories about that: Because when the woman understood what the doctor wanted, and the doctor understood that she feared for her own life, it was often too late and the baby had died. The conclusion is that perinatal mortality is related to social and cultural practises.

**Female genital mutilation**

Birgitta Essén and Sarah Johnsdotter also looked at how motives for female genital mutilation change in exile. Through interviews they found out that even though circumcision is practiced in Somalia, in Sweden it was questioned among the
women, who met Moslem groups in Sweden that did not circumcise their daughters. Furthermore marital patterns changed.

So obviously these women are able to change their habits and traditions. All anthropological and medical research on female genital mutilation has shown that the problem now is in the Swedish government and the NGO-groups, not among the Somali groups.

In Sweden so far there is no evidence of female genital mutilation, and the law that forbids it has never been used. We do not say that it is not going on, but all research shows that it is being reduced enormously. This shows that tradition can be difficult to change, also in our own, my community, even when research backs it up.

Birgitta Essén advised to always stay professional – to show no soft nor hard feelings. To treat each patient as an individual independently of gender, ethnic, social or cultural background. And finally that because physicians have the advantage of communicating with their patients – they should remember to use that possibility.

Conclusion

In clinical practice it is important to:
1. Support research from a migrant perspective
2. Take part of research results
3. Support employment of health care providers with foreign background (culture brokers)
4. Clinical guidelines should be based on the minorities as well as the majority of the population
5. Revise guidelines for utilising interpreters
6. Establish routines of quality controls and audits in a migration perspective

Immigrants with skills in health and medical care is an unexploited resource for public health work, as it is difficult in Sweden to get a license to practise. On the other hand Swedish health care staff has experienced many difficulties when encountering people from other cultures, and they often feel insufficient because of lack of knowledge.

The staff also feel they are wasting their time when immigrants want to be treated for a cold, which the doctor or the nurse feel they should treat themselves. A fact which could be easily explained to the patient by a person with social competence.

On this background a project was established where immigrants with medical skills from their home countries give information about health to other immigrants in their mother tongue.

“The idea is to use the method of empowerment, and we are health promoters and advisers at the same time. We try to give the patients all the results and all the facts. The rest they must do themselves”, Karin Persson and Nabil Rauf said.

Goals

- To prevent ill health among chosen language groups
- To elaborate new methods for preventive work in the area of public health
- To clarify the profit of a multicultural health care sector for the society as a whole
- To promote integration

Target group

Families with children or expecting children and youths age 16-24 years in need of health care advice in their mother tongue

Languages

Bosnian, Somali, Albanian, Dari, Pashto, Kurdish, Persian

Method

Health advice is given on an individual level, as well as on a group level. The contents of the information is decided by need and demand of the target group and the partners
Fundamental themes

The organisation of the health care system, self-treatment, virus/bacteria, stress, sleeplessness, mental health, food/diet, physical exercise, tobacco, alcohol, drugs, dental health, sexual health.

A lot of immigrants suffer from mental instability, and it is important to explain to them how the mental state affects the body and also influences the structure of the family.

It used to be the father who worked and took care of the family, and the mother took care of the home and the children. When they come to Sweden that suddenly changes, because the father might not find work and the family is living on social benefits.

Intensive education programme

The health advisors in the project all have a professional background and are Swedish speaking:
- 3 medical doctors from Iraq, Kosovo and Afghanistan
- 2 physiotherapists from Bosnia and Kurdistan
- 1 medical carer from Somalia
- 1 pharmacist from the Middle East
- 1 dentist from Iraq
- 1 nurse from Kosovo
- 1 laboratory assistant from Afghanistan
All health advisors go through a three month intensive education programme, before they start working. The courses take place at the University of Malmö, the University Hospital of Malmö and The Red Cross.

The project works with constant quality assurance through an ongoing dialogue in the work team, along with feedback from the nursing staff and other personnel in relevant areas.

It is a joint project between Region Skåne and the town of Malmö, which are both financing the programme.

**Results**

**Health advisors:**
- Increased motivation and bigger self esteem
- Improvement of the Swedish language
- Personal progress and larger network

**Participants:**
- Efficiency gain
- Increased knowledge and understanding
- Employed health advisors

**Target group:**
92 percent asked for more information

**Conclusion**

There is a need of implementing international health advisors as a profession, but further methods have to be elaborated.
Notes from workshops

Notes from workshop 1
Cultural misunderstandings in the health system

Chairman: Maria Kristiansen

Cultural misunderstandings is a very broad concept. One part of it covers myths surrounding ethnic minority patients and health personnel, another covers the "real" barriers affecting the meeting between ethnic minorities and different spheres of the health care system. The myths may constitute real barriers in the meeting with the patient, as some issues are preconceived and some issues are not handled in the same way as they might have been in relation to majority patients.

Cultural misunderstandings e.g. concerns the relationship between patient and health care professional i.e. how to be a good patient, the understanding of health and disease, the family/social network – what are their roles supposed to be? The role and status of women in ethnic minority families.

An important point is that health care professionals do not need to know everything about cultural differences but they need to be aware of their own shortcomings. They must avoid the common tendency to look upon a patient from an ethnic minority group as a representative of a curtain group rather than looking at the person as an individual with individual needs. Members of the health care system are trained to ask questions, but not trained to listen. It is important that questions be asked in a proper and respectful manner in order to build up trust between the caregiver and the patient. And it is important to remember that communication is verbal as well as non-verbal and goes two ways.

The use of trained interpreters is crucial especially when it comes to informing a patient about a serious diagnosis and treatment. Using children and/or other family members should be avoided, since cultural differences may mean that they will try to protect the patient from being informed about a serious diagnosis.

The group recommended that each patient should have access to information on social, economic and health issues in his or her own language, and that the institutions must establish guidelines on the use of authorized interpreters.
Notes from workshop 2
Cultural difference as a resource

Chairman: Arild Aambø

Every culture has rituals to handle grief, and Arild Ambø was once asked to talk to a group of migrant women about how to handle grief. Interesting differences came up: Some Muslim women grieved for 30 days, others for 40 days, and men grieved for a shorter period of time than the women. The women ended up asking the important question: How do we know when we have grieved enough? The women talked and gathered in small groups and cried. At the following meeting they were all very cheerful.

The important thing was that the question came from the women themselves. They were able to use their own resources and each other to find solutions and ways of coping.

There are gender differences when it comes to preventive work, and there are far more health promoting projects involving women than men, e.g. groups for mothers, through health visitors and in women’s houses. Men are more difficult to reach, they simply do not gather in small groups and share their life experiences. Talking and sharing life experiences is a typically female way of coping. If asked, women will tell their life story and about their family, and this is an important way of identifying their resources. The group agreed that different strategies are needed depending on whether the target group is women or men, and it was discussed how to reach the men.

Henrik Overballe from Cross-Over, a project working with ethnic groups and hiv/aids in Denmark, told that the project works by making the different groups partners in the project instead of clients. For instance a Somali organization in Aarhus got the funds to give out information about hiv/aids. Four doctors of Somali origin were part of the project.

Henrik Overballe stressed the importance of making projects with built-in sustainability.

You have to trust people and take them seriously, and they have to feel ownership for the project. He also said that, as Danes, Swedes etc. we cannot do this work ourselves, as we do not speak the language of the different ethnic minorities and we do not know the cultural codes.
Notes from workshop 3
Smoking is a health hazard

Chairmen Ingrid Stevens & Lisen Sylwan

Ingrid Stevens, project manager for risk groups at Stivoro, a Dutch non-smoking organisation, told how ethnic minorities can be informed about the risks of smoking and about smoking cessation. In the Netherlands there are 250 health educators of various ethnic backgrounds who inform and educate immigrants about the health care system, disease prevention, child rearing etc. Stivoro provides these health educators with a basic, but broad education about smoking prevention: information on the constituents of smoke, taking up smoking by young people, ETS and cessation.

Motivational interviewing is a useful method to initiate fruitful discussions about smoking and to avoid misunderstandings which are common when there are language barriers.

Some immigrants are illiterate and/or have a poor knowledge of the language spoken in their new country. Here it might be an idea to use cartoons with very simple texts to explain the risks of smoking.

Finland does not attract many immigrants, and the ones who come generally have a higher education, Satu Lipponen told. But there is very little knowledge about the various ethnic groups and the first priority is to fill that gap. Iceland also has few immigrants, and Amal Tamimi said that nothing in particular is done to reach them concerning smoke prevention.

All the Nordic cancer societies run anti smoking programmes directed towards young people. The workshop group did not consider initiatives for youths from minority groups an urgent need, as anti smoking programmes are common in schools, and thus available for minority groups as well.
Notes from workshop 4
Channels of information

Chairman: Mirka Mozer

In Denmark the AIDS-foundation has started three different projects to further ethnic equality, when it comes to HIV/AIDS, Mirka Mozer from the Danish organization Cross-Over said. Different cultures have different conceptions of illness, and it is important to take these differences into consideration, when you inform people and give advice about HIV/AIDS. The discussion in the group showed that experiences from working with information about HIV/AIDS to ethnic groups are highly relevant, when you transfer them to the cancer sphere.

The group exchanged experiences on the use of leaflets in the information work. Several participants had mailed letters to the persons they wanted to reach, but told that the result was disappointing. Often only a few people show up to a meeting, and it might be better to use established networks. Experience shows that it is easier to make the women come to meetings, and besides the men are often working during the day.

The translation of leaflets is expensive, and direct translations of existing leaflets sometimes create problems, so it might be simpler and less expensive to write a new text and translate that.

Public offices and volunteer organizations often have good ideas and the will to make them work. Therefore you should prepare a binding plan, especially about financing the information material, when you collaborate.

An idea is to establish a cooperation between the Nordic countries about ideas for information to minority groups, for example coordinated by the Nordic Council of Ministers. This NCU-conference could be the starting point for such cooperation.

It is often easier to reach the well educated immigrants, therefore it would be of great assistance to prepare lists of doctors and other professionals with a different ethnic background, who might be a resource in the information work.

It is important to seek advice from the minority groups about where and how information material should be put out, so that it does not end up on a dusty shelf in the libraries. It is also important to build up trust and to have an open dialogue. It can be achieved by asking the persons who seek help about what they think themselves.

There is a symbolic effect, when a person receives a brochure ‘in my language’ – it shows you are taken seriously.
Presentation of speakers

Arild Aambo

GP, qualified supervisor and Master Practitioner. Has 20 years of experience in clinical communication within family treatment, clinical hypnosis and individual therapy. Established in 1994 the Primary Health Care Workshop (PMV – Primærmedicinsk verksted) in Oslo, a project for developing health promoting means and dialogue for a multicultural setting. Head of PMV in addition to NAKMI-engagement.

Fahimeh Z. Andersen

MD, Senior registrar at the Department of Oncology, Herlev Amtssygehus. Qualifies as a specialist in oncology next year. Born in Iran, came to Denmark 19 years old. Fahimeh Andersen has been, and still is, occupied with immigrants' and refugees' problems when meeting the Danish health system.

Mohamed Gelle

Project manager at DRC, The Danish Refugee Council, and director of a local TV channel (GL TV) in Copenhagen. Came to Denmark as a refugee from Somalia in 1983 with a secondary school certificate and a bachelor of naval studies from Alexandria, Egypt. After an intensive Danish language course, he started and completed a master or captains certificate at Svendborg Navigation School and has been sailing as an officer in the Danish merchant fleet for more than 10 years. In the meantime Mohamed Gelle studied at the University of Copenhagen and promoted different kinds of social work on a voluntary basis, which led to different board posts, among these he held the post as chairman of the largest ethnic minority federation in Denmark (IND-sam).

Anders Ekbom

Associate Professor in surgery, Professor in epidemiology 2000 at Karolinska Institutet, The Institution for Medicine at the Karolinska University Hospital, Solna, Stockholm. Adjunct Professor at Harvard School of Public Health.

Birgitta Essén

MD, PhD. Reproductive Health and Rights in a migration perspective is approached in an interdisciplinary way involving gynaecological and obstetrical issues with public health aspects. These also include legal, social, and cultural aspects of safe motherhood, sexually transmitted infections and gender based violence. The clinical goals of the research have been to develop tools for appropriate health services to women in migration situations. By using both quantitative and qualitative methods,
the research projects have identified, not only social and biological risk factors, but also explored patients and care givers attitudes and experiences of care. Crucial for successful research in a migration perspective has been to collaborate with culture brokers.

**Bengt-Erik Ginsburg**

BEG, MD, PhD, senior consultant, pediatrician, with more than 30 years of clinical experience and 25 years work with ethnic minorities, migrants, asylum seekers and refugees in Sweden. Lecturer in intercultural communication for students and professionals. Member of an advisory board on asylum seeking children at Ministry of Foreign Affairs. International experiences: Council of Europe (Brussels), International Center for Migration and Health (Geneva), Child Health in China (Beijing, Chang Sha, Xin Dao with Unicef) and Venezuela, Human Rights Foundation and the Red Cross in Turkey (Ankara, Ismir, Adana, Diyarbakir and Istanbul).

Recently employed at the Transcultural Centre, Stockholm County Council, for clinical consultation and training (www.sll.se/transkulturelltcentrum)

**Nina Hamerik**


Publications: Dynamisk Tolkning (Chapter on interpretation programmes for community interpreters, Socialpædagogisk Forlag, in Danish only – 1988); Notetaking techniques for consecutive interpreters (CBS, 1995); Community interpreter programmes in Denmark (The Critical Link, Vancouver, 1998); Tolkning & tolkeetik (HK/LAK – 2003 – in Danish only) ; Article in “Månedsskrift for praktisk læge-gerning” (Lise Dyhr & Nina Hamerik – 2004).

**Amneh Hawwa**

Born in Nazareth. Came to Denmark 30 years ago. MD from the University of Copenhagen in 1989. Trained as general practitioner. Sexologist. Medical translator in Danish-Arabic. Member of Amnesty International’s medical team. Board member in The Danish Association for Clinical Oncology. Co-author of several books about immigrants, health and sexuality. Now training in obstetrics and gynaecology at the University Hospital in Odense.
Iben Holten

D.M.Sc. Trained in surgical pathology. Has been working in university hospitals in Copenhagen. Iben Holten is now working as project manager at the Danish Cancer Society. Main areas: Screening and information to ethnic minorities.

Allan Krasnik

MD. Allan Krasnik is professor at the Department of Public Health at the University of Copenhagen. He has over a number of years worked with research and education concerning dissimilarities in access to the health services among various social and ethnic minority groups.

Maria Karen Kristiansen

Master of Sciences in Public Health, University of Copenhagen. Has recently finished her thesis about the meeting between hospital staff and immigrant patients. The purpose has been to illustrate which problems hospital staff experiences when meeting ethnic minority patients and how they experience these patients. The thesis also focuses on which strategies the staff uses and which tools they need in order to further communication. Project leader at an education association in Copenhagen for courses about health promotion, empowerment and prevention among three groups of immigrant women.

Mirka Mozer

Project manager for Cross-Over. MA in Danish and Art History. Cross-Over is an HIV/AIDS preventive project targeting ethnic minority groups in Denmark.

Tom Nauerby

Ph.D. in social anthropology. Born in 1959. Senior lecturer at the University College of West Jutland, working part time at the nursing school and part time at the department of research and development. Current research-projects: ‘Lifestyle and Health Behaviour of Iraqis living in Esbjerg’. Adviser and project manager for several ongoing projects in relation to health, social services and evaluation; including ‘Recovery for Persons with Mental Illnesses in the County of Ribe’ and ‘Accreditation of the Bachelor Degree in Nursing’.

Karin Persson

Bachelor degree in Middle East Studies, focusing on Turkey, at Uppsala University. MA in Social Anthropology at SOAS, University of London, September 2003. Now working as project secretary in the project International Health Promoters. Working as coordinator between the project and various partners, as well as supporting the...
health informers and the project leader in their work. Very interested in multi-cultural groups in all aspects.

**Peter Meidahl Petersen**

MD, Ph.D. Speciality: Clinical Oncology. 10 years experience in clinical oncology. Consultant at the Department of Prevention and Documentation, The Danish Cancer Society since 2001. Experiences with patients from ethnic minorities from the clinical work and from one year’s clinical work in Toronto, Canada.

**Eero Pukkala**

Director of Statistics at the Finnish Cancer Registry, Institute for Statistical and Epidemiological Cancer Research, Helsinki, and Docent in epidemiology at the Medical Faculty of the University of Tampere. Has written about 350 peer-reviewed scientific publications on occupational, environmental and life style risk factors of cancer, evaluations on interventions and survival studies. Coordinator of numerous national and international cancer-related research projects and expert teams.

**Nabil Rauf**

My name is Nabil Rauf Al-Dujaily and I’m from Iraq. I’ve actually worked as an anaesthetist in my homeland, but in Sweden I’ve been working as a health informant while getting ready to my medical examination in the Swedish language.

**Ingrid Stevens**

Projectmanager adult smoking at STIVORO for a smokefree future in the Netherlands since september 1998. Works on minimal interventionstrategies quit smoking in health care settings and has developed materials to reach the immigrant groups in the Netherlands. Has used an existing network of immigrant health educators in the Netherlands to inform immigrants on the subject of smoking and ETS.

**Hans Storm**

MD. Director of Cancer Prevention and Documentation at The Danish Cancer Society. He started his career in epidemiological cancer research at the Danish Cancer Registry in 1981, after being fully licensed in medicine, and was head of the registry from 1986 to 1997 and also Director for the Division for Cancer Epidemiology 1991-1997. He has served on several international scientific committees evaluating research and research organisations. He was appointed member of the WHO Cancer Expert Panel 1993 and has served as a consultant in the Sudan, Nigeria and Pakistan. He has been a member of the European Union Cancer Expert Group in cancer prevention since 2001.
**Sadia Syed**

Social worker since 1994. Wide experience with legislation in the social field, marginalized groups, ethnic minorities and voluntary work. Member of The Danish National Council for social marginalized groups and the International Committee of The Danish National council on Social welfare. Has made a survey of the support and care person scheme for mentally ill immigrants and refugees – a qualitative survey, April 2003. The survey was made in cooperation with the Danish Red Cross. Has made a survey about how employees with ethnic minority background consider Novo Nordic as a workplace, September 2001. This survey was made in cooperation with the TLS-consultants.

**Alma S. Walther**

BA in Economy and Tourism from the University of Sarajevo. Speaks fluently English, Danish, Swedish and Slovenian and has worked as a translator for the last 6 years. In 1996/97 she spent 10 months in Sarajevo – English-Bosnian – for a mission from Brussels (CAFAO). Since the beginning of 2000 she has worked in Denmark. In Aalborg she has participated in an extensive course in translation for psychologists (the county of Northern Jutland) and is at present doing an extensive course in translation for translators working in the health system (the subjects being illness, prevention, ways of appeal etc.).

**Inge Wittrup**

Project-coordinator in the County of Aarhus, mag. art. & Ph.D. in social anthropology. Main areas of responsibility: health promotion among ethnic minorities; health promotion and prevention in primary care.