

Breast cancer screening participation among Turks and Moroccans in the Netherlands: exploring reasons for nonattendance

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In the Netherlands, attendance rates for breast cancer screening are much lower among Dutch women born in Turkey and Morocco than they are among native Dutch. The reasons for this trend are not yet known. Currently, mortality and incidence rates for these migrant groups are much lower than those of the native population. However, studies show convergence towards the rates of the native Dutch population. We therefore performed a narrative literature review to study the reasons behind the low participation rate for breast cancer screening among Turkish and Moroccan women in the Netherlands. No truly relevant research on this topic was available. Information acquired from articles only applicable to certain areas of the research question showed that reasons pertaining to lack of awareness and knowledge, organizational issues and socio-cultural aspects are most likely to be responsible for the low attendance. To increase attendance

rates, more research is needed to obtain insight into these aspects and into the reasons given by Turkish and Moroccan women. *European Journal of Cancer Prevention* 18:349–353 © 2009 Wolters Kluwer Health | Lippincott Williams & Wilkins.

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Introduction

In the Netherlands, a gradually expanding national breast cancer screening programme has been in place since 1990. The programme is coordinated both centrally and regionally, and is implemented by nine regional foundations in a standardized manner. At present, the programme is designed for screening women aged between 50 and 75 years. These women receive an invitation letter (accompanied by an information brochure) to take part in the screening programme every 2 years (Den Broeder, 2008). The mammography is free of charge, takes place in a specialized research centre or mobile research bus ('mammobile') and is performed by specially trained radiographic assistants (Anonymous, 2009). The goal of the programme is to reduce breast cancer mortality rates (Van der Wilk, 2007), which, in the Netherlands, are among the highest in the world (Van der Wilk, 2006). Research has shown that screening efforts have been successful in achieving this goal (Otto *et al.*, 2003).

Dutch society consists of a diverse group of ethnicities, the composition of which is changing with time. At present, approximately 11% of the Dutch population consists of non-Western migrants (Anonymous, 2008). This study uses the CBS definition of non-Western migrant: migrant with its group of origin being one of the countries on the continents Africa, Latin America and Asia (excluding Indonesia and Japan) or Turkey. The majority live in the four major cities in the western part of

the country, making up 20–30% of the local population (Anonymous, 2006). The largest groups are guest workers and their families from Turkey and Morocco who started coming to the Netherlands in the late 1960s (each now account for approximately 2% of the population; Anonymous, 2008) and migrants from the former Dutch colonies of Surinam and Netherlands Antilles (Stirbu *et al.*, 2006).

These groups differ from the native population, not only in breast cancer mortality and incidence rates (Visser *et al.*, 2004; Visser and van Leeuwen, 2007), but also in healthcare use behaviour (Anon, 2006; Koppenol-van Hooijdonk *et al.*, 2007). With regard to breast cancer screening participation, attendance rates for migrant women born in Turkey and Morocco are particularly low. The attendance rate for the women born in the Netherlands is 79%, whereas Turkish and Moroccan migrant women have an attendance rate of 44 and 37%, respectively (Visser *et al.*, 2005). Currently, mortality and incidence rates are still much lower than those of the native population (Visser *et al.*, 2004; Visser and van Leeuwen, 2007). However, worldwide research supports the hypothesis that breast cancer risk among migrants increases with generation (Zeeb *et al.*, 2002; Andreeva *et al.*, 2007). Furthermore, migrant mortality rates have been shown to be converging to those of the native Dutch population (Stirbu *et al.*, 2006).

To be able to reduce their breast cancer mortality rates, now and particularly in the future, knowledge about the reasons for low attendance at the Dutch breast cancer screening programme among Turkish and Moroccan migrant women in the Netherlands is needed. The objective of this study is to explore the reasons for nonattendance of Turkish and Moroccan women at the Dutch breast cancer screening programme by means of a narrative literature study.

Methods

We searched the literature with PubMed (no date restrictions), EMBASE (1990–2008), PsychINFO (no date restrictions) and *www.find-health-articles.com* (no date restrictions). We also used literature databases on websites from organizations concerned with public health or cancer in the Netherlands (*www.riem.nl*, *www.nivel.nl*, *www.cbs.nl*, *www.kwfkankerbestrijding.nl*). We started our search using the following search terms: ‘Breast Neoplasms’ or ‘Breast cancer’; ‘Transients & Migrants’ or ‘Migrant*’; and ‘Netherlands’ and ‘Mass screening’ or ‘Screening’. Owing to a lack of results, we extended our search by removing different search terms in various combinations. We also changed ‘Transients & Migrants’ or ‘Migrant*’ to ‘Turkey’ or ‘Turk*’ or ‘Morocco’ or ‘Moroc*’, and replaced ‘Breast Neoplasms’ or ‘Breast cancer’ with ‘Neoplasms’ or ‘Cancer’. Finally, we added the following string of search terms: ‘Mammography’ and ‘Patient compliance’ or ‘Attendance’ and/or ‘Transients & Migrants or Migrant*’. Reference lists of found articles were examined to find additional relevant literature.

We excluded articles that researched migrants within the United States, Western migrants or people migrating within a country because of differences in healthcare systems and migrant characteristics. We also excluded articles researching aetiology, prevalence and mortality rates, usefulness of introducing a breast cancer screening programme, usefulness of breast self-examination, and articles researching epidemiology of different cancers or diseases. Finally, we excluded articles that were not available in the English or Dutch language. We excluded these articles by reading the title, abstract or sometimes the whole article.

Results

Not one article found explored the reasons for non-attendance of migrants at a breast cancer screening programme in the Netherlands or in any other country. Nine articles were found that were in some way relevant, for instance, by describing reasons for non-attendance of Turkish and Moroccan women at the cervical cancer screening programme. Table 1 summarizes the contents of the articles found.

The results of the literature study can be classified into two major groups. The first group is related to socio-demographic factors. Kreuger *et al.* (1999) found that a low percentage of migrants and single/divorced women and a high socio-economic status all correspond to a high attendance rate at the cervical cancer screening programme, whereas van Leeuwen *et al.* (2005) and Visser *et al.* (2005) found significantly lower attendance rates at the cervical cancer and breast cancer screening programmes for Turkish and Moroccan women, respectively, compared with those of native Dutch women. The other six articles described factors associated with screening behaviours. The causes for nonattendance can be divided into three groups: awareness and knowledge, organizational issues and socio-cultural aspects.

Awareness and knowledge

Research among women in Turkey showed that the use of mammography in the absence of a screening programme correlates positively with a higher perception of risk, a positive family history of breast cancer and simply having heard about breast cancer. Having heard or read about mammography was the strongest predictor of having a mammography. The majority of the research population, however, had never heard or read about breast cancer or mammography. Television and radio were the largest sources of information about breast cancer (Çeber *et al.*, 2006; Seeginli and Nahcivan, 2006). The absence of symptoms was one of the reasons for Turkish migrant women not attending the cervical screening programme (Lale *et al.*, 2003). One of the most frequently stated ideas of the women about increasing participation was receiving more information about the screening procedure (Verhoeven, 1994; Lale *et al.*, 2003), whereas lack of knowledge about cervical cancer and its screening programme was higher among nonattending Turkish women (De Jong, 2005).

Organizational issues

A major portion of Turkish migrant women did not attend the cervical cancer screening programme because they had not received an invitation letter (Lale *et al.*, 2003). In contrast, invitation by and satisfaction with the general practitioner (GP) led to more participation in the cervical cancer screening programme (Lale *et al.*, 2003; van Leeuwen *et al.*, 2005). When asked how to increase participation, a frequently mentioned response was invitation by the GP (Verhoeven, 1994; Lale *et al.*, 2003). Attending Turkish women understood the invitation letter better than those not attending (De Jong, 2005).

Socio-cultural aspects

A major reason for non-attendance at the cervical screening programme by Turkish women was the lack of mastery of the Dutch language (Lale *et al.*, 2003).

Table 1 Characteristics of relevant articles

References	Setting	Screening programme	Participants	N cases	Study design	Research topic	Results
Kreuger <i>et al.</i> (1999)	The Netherlands	CC	All women aged 35–53 years in Rotterdam area invited to screening once during 1992–1994	Total: 70 621	Cohort; screening population and laboratory registers	Socio-demographic differences in attendance	High SES, low percentage of migrants, single/divorced women correspond to high attendance
Van Leeuwen <i>et al.</i> (2005)	The Netherlands	CC	Women aged 30–60 years living in southwest Netherlands, invited between 1998–2001	Total: 251 446, T: 4044, M: 1366	Cohort; screening registers	Socio-demographic differences in attendance	Significantly lower attendance rates for T & M compared to D
Visser <i>et al.</i> (2005)	The Netherlands	BC	All women aged 50–74 years invited for screening between 1995–2002 by CCCA	Total: 724 490, T: 85 666, M: 8017	Cohort; screening and population data registers	Socio-demographic differences in attendance	(i) Significantly lower attendance rates for T and M compared with D (ii) Attendance rates especially low for women over 60 years of age
Verhoeven (1994)	The Netherlands	CC	T and M aged 35–55 years living in Leiden and surrounding area recruited through direct contact and snowball methods	Total: 25, T: 12, M: 13	Cross-sectional; semistructured interview with topic list	Factors associated with nonattendance	(i) Not having received or understood (Dutch) invitation letter (ii) Lack of knowledge about examination (iii) Fear/shame of (results of) examination (iv) Lack of satisfaction with GP
Lale <i>et al.</i> (2003)	The Netherlands	CC	T living in Amsterdam recruited through community centres and snowball method	Nonattendees: 27 Attendees: 50	Cross-sectional; personal interview through semistructured questionnaire	Factors associated with nonattendance	(i) Lack of mastery of Dutch language (ii) Lack of satisfaction with GP (iii) Not having symptoms (iv) Not having received invitation letter
De Jong (2005)	The Netherlands	CC	T aged 30–60 years living in Twente recruited through health care centres, direct contact and snowball methods	Total: 183	Cross-sectional; structured written questionnaire in Dutch or Turkish	Factors associated with nonattendance	(i) Lack of knowledge of CC and CCS (ii) Not understanding invitational letter
De Nooijer <i>et al.</i> (2005)	The Netherlands	CC	Women aged 30–60 years living in southwest Netherlands, invited between 2000 and 2003	Total: 237 719	Cohort; screening registers	Factors associated with screening behaviour	(i) Participation rate higher after invitation by GP versus GGD (ii) Bigger rise in attendance rate in T and M versus D
Çeber <i>et al.</i> (2006)	Turkey	BC	Nurses and midwives working in primary health care centres, older than 20 years of age	Total: 215	Cross-sectional; written questionnaire	Factors associated with screening behaviour	(i) Higher risk perception when family history is positive (ii) Higher risk perception gives rise to more mammography use
Secginli and Nahcivan (2006)	Turkey	BC	Female health centre attendees, aged 20–70 years	Total: 656	Cross-sectional; written questionnaire and CHBMS	Factors associated with screening behaviour	Mammography use associated with: (i) Having heard of mammography or BC (ii) Having gynaecologist as regular physician (iii) Having health care insurance

BC, breast cancer; CC, cervical cancer; CCCA, comprehensive cancer centre Amsterdam; CCS, cervical cancer screening; CHBMS, Champion's Revised Health Belief Model Scale; D, native Dutch women; GP, general practitioner; GGD, local health authority; M, Moroccan women; SES, socio-economic status; T, Turkish women.

Discussion

Reasons for nonattendance at the screening programmes related to knowledge and attitudes (such as not having symptoms, doctor already examined breasts, not interested, ethical reasons) can also be found in studies in the overall population (Aro *et al.*, 2001). It is not surprising that these factors are prominent in migrant women, as we know that Turkish and Moroccan women have little knowledge about either their own body or disease in

general (Van den Muijsenbergh and Lagro-Janssen, 2006). In addition, they have a low level of education and often a low socio-economic status, factors also associated with low attendance rates (Kreuger *et al.*, 1999; Van der Velden *et al.*, 1999).

Literature on factors leading to nonattendance among the general population also describes reasons related to organization of the screening programme. Practical

problems for the women (including too busy at work or at home, forgetting the appointment, would have lost salary) and reasons related to organization of the screening programme itself (such as trip to the screening centre difficult, could not reschedule appointment and did not receive invitation) were mentioned as important factors (Aro *et al.*, 2001). A meta-analysis on mammography screening attendance by Denhaerynck *et al.* (2003) also highlighted the importance of organizational structure. It revealed that invitation to the mammography screening by personal or telephone contact can increase attendance dramatically. One of the most interesting results was the importance of the GP. As the role of the GP as access point for the rest of the Dutch healthcare system is more important among migrant groups (Uiters *et al.*, 2006), the GP could play an important role in breast cancer and breast cancer screening awareness and knowledge.

A salient result with regard to socio-cultural factors of low participation in the cervical cancer screening programme was lack of proficiency in the Dutch language. Demographics show that approximately 30% of the Turkish and Moroccan migrant women experience difficulty in understanding the spoken or written Dutch language on a daily basis (Dagevos and Gijsberts, 2007). In addition to this, a large proportion of the Turkish and Moroccan women have a very low level of education and some of them are illiterate (Keuzenkamp and Merens, 2006). The fact that the majority of the invitation and information materials is both written and in Dutch could form a serious barrier. The acquirement of information in a more social context is also not optimal, as 35% of Turkish and 30% of Moroccan migrants never have contact with the native Dutch population in their leisure time (Dagevos and Gijsberts, 2007). Taking this into account, a large proportion of Turkish and Moroccan migrant women are probably largely dependent on knowledge provided by their countries of birth. It is therefore of relevance to know that in Turkey, prevention and awareness activities are very low and there is no screening programme (Çeber *et al.*, 2006; Secginli and Nahcivan, 2006). Official literature on screening programmes in Morocco was not found; however, a Moroccan news site mentioned a new widespread awareness campaign and the opening of the first breast and cervical cancer screening centre in 2008 (Touahri, 2008).

Literature on coping mechanisms of migrants with regard to cancer shows that awareness and knowledge are intertwined with socio-cultural aspects. The coping mechanisms of migrants differ substantially from those of the native population. Important factors in coping with cancer are belief in supernatural forces, lack of knowledge about symptoms and disease mechanisms (e.g. believing that cancer is contagious), fear of social isolation and

limited culturally determined means to discuss the illness (Anonymous, 2006; Koppenol-van Hooijdonk *et al.*, 2007).

Owing to the low number of relevant articles found, we did not use poor research quality as an exclusion criterion. We did, however, check for quality characteristics such as sample size, relevance and size of study population, confounding factors and bias, and included these in our considerations with regard to the relevance of the conclusions drawn. Although this constitutes an overall limitation in our review, the limited literature makes drawing conclusions about reasons for nonattendance of Turkish and Moroccan women at the Dutch breast cancer screening programme impossible. Therefore, further research into these reasons is needed. Points of particular interest for this research are the aspects described above and the reasons women themselves give.

Visser *et al.* (2005) argued that as Turkish and Moroccan women have a very low cancer risk at present, a passive attitude towards their low screening attendance is justified. However, worldwide research has shown that cancer mortality rates of migrants have the tendency to approach those of the native population (Zeeb *et al.*, 2002; Andreeva *et al.*, 2007). However, the use of healthcare across generations is complex, and does not necessarily follow acculturation (Uiters, 2007). In addition, as the Dutch government is bound by international treaties (Anonymous, 2002, 2007), equal access for migrants to screening programmes must be strived for from both an ethical and a legal point of view.

Conclusion

Forty-four percent of Turkish and 37% of Moroccan women in the Netherlands do not attend the breast cancer screening programme. Our literature search of the reasons for this low rate of participation revealed that no truly appropriate research is available on this topic. However, from the more general literature found during our search, we have extracted three major groups of reasons for nonattendance that are most likely to be applicable to breast cancer screening attendance of Turkish and Moroccan women in the Netherlands: lack of awareness and knowledge, organizational issues and socio-cultural aspects. To understand the reasons why breast cancer screening attendance is so low, we suggest that future research be directed towards these areas by interviewing these women themselves.

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