Knowledge, information sources and awareness regarding breast cancer screening : a comparative study in Lugano/Switzerland and Amsterdam/Holland

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Scoms Correction note

Schulz, P. J., & Meuffels, B. (2009). Knowledge, information sources and awareness regarding breast cancer screening: A comparative study in Lugano/Switzerland and Amsterdam/Holland. *Studies in Communication Sciences*, 9(1), 249-264.

In the introduction to our article 'Knowledge, information sources and awareness regarding breast cancer screening: A comparative study in Lugano/Switzerland and Amsterdam/Holland', in two cases a single phrase was taken from the following articles without offering proper reference to these publications (1) "Using the European guidelines to evaluate the Norwegian Breast Cancer Screening Program", by Solveig Hofvind, Berta Geller, Pamela M. Vacek, Steinar Thoresen, and Per Skaane (*European Journal of Epidemiology* 22 (2007): 447-455); (2) "Initiation of Population-Based Mammography Screening in Dutch Municipalities and Effect on Breast-Cancer Mortality: a systematic review", by Suzie J. Otto, Jacques Fracheboud, Caspar W.N. Looman, Mireille J.M. Broeders, Rob Boer, Jan H.C. L. Hendriks, André L.M. Verbek, Harry J. de Koning; the National Evaluation Team for Breast Cancer Screening (*The Lancet* 361 (2003): 1411- 1417).
If we violated the authors' rights, we regret this and apologize for the missing citations. Although these errors concerned phrasings rather than research findings, and despite the fact that this does not affect the empirical data of the study, nor the interpretation of these data nor the conclusions that we draw, we nevertheless believe an apology is due.

Sincerely Peter J. Schulz & Bert Meuffels

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KNOWLEDGE, INFORMATION SOURCES AND AWARENESS REGARDING BREAST CANCER SCREENING: A COMPARATIVE STUDY IN LUGANO/SWITZERLAND AND AMSTERDAM/ HOLLAND

Knowledge and insight in women's knowledge regarding breast cancer recommendations and the possible influence of this knowledge on women's actual and future behavior are still lacking. A survey was performed in Lugano, the major city of the Italian-speaking part of Switzerland, and Amsterdam, the major city of Holland. In Switzerland opportunistic mammography screening is the rule in most cantons, whereas in Holland, as part of a nationwide mammography-screening programme, women aged 50–75 are invited to a mammography every second year. Data collection was done by means of a face-to-face written questionnaire. No significant differences between Lugano and Amsterdam were found regarding general knowledge, but Amsterdam women show better specific knowledge of the age groups for whom screening is recommended. Lugano women are more concerned about breast cancer, use more information sources, have a higher intention to go for a mammography, practice more breast self-investigation, have had more mammograms in the past, whereas the Amsterdam women claim to have more experience with breast cancer among their families and friends. As knowledge of the recommendations seems to play a role in women's proper future behavior regarding screening, efforts should be made to improve women's knowledge, especially in Ticino.

Keywords: breast cancer, knowledge regarding mammography.

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1. Introduction

Breast cancer is one of the most common cancers in Western industrialized countries: one in every ten women will develop breast cancer during her lifetime. The mortality of this cancer is high. In Europe, 2004 estimates indicated 371 000 new cases of breast cancer diagnosed and 129 900 breast-cancer-related deaths (Boyle & Ferlay 2004). Mortality rates rose from 1951 to about 1990 but fell afterwards in Western countries. Among the various reasons for this decline in Western Europe, Australia, and the US, the introduction of mammographic screening programs is often mentioned (Tabor et al. 2003; Smith et al. 2004; Veronesi et al. 2005; Vainio & Bianchini 2002; Nystrom et al. 2002). The potential disadvantages of screenings are unnecessary anxiety and morbidity related to the diagnostic work up, false positive and false negative screening examinations, overdiagnosis, economic costs and the exposure to radiation (Vainio et al. 2002; Goetzche et al. 2006).

In the countries where this study was conducted (i.e. in Switzerland and in Holland), the situation is quite different in respect to screening programs – and that is precisely the reason for comparing these two countries. Switzerland is a country with one of the highest mortality rates from breast cancer worldwide (Levi et al. 1999). Current Swiss guidelines on mammography screening recommend a mammogram every 2 years for women 50 to 70 years old and no routine screening below age 50 and above age 70 (Swiss Cancer League). Cost for mammography is covered by health insurance when a physician prescribes it. Screening programmes are in operation only in two French-speaking cantons.

In Holland breast cancer is also the most frequent type of cancer among women; each year more than 11 000 cases of breast cancer are observed, implying that one out of nine women will get breast cancer in her life. Each year more than 3500 women die, due to the consequences of breast cancer. Between 1989 and 1997, Holland gradually implemented a nationwide mammography-screening programme for women aged 50–75 years. By 1997, women of the target age group were receiving invitations for screening every other year, and results of early outcome assessments (de Koning et al. 1991; National Evaluation etc. 2001) indicate that the programme is having a positive effect. It is estimated that the mortality rate among women

between 50 and 75 is reduced by 25 %, thanks to the programme (Oldenburg et al. 2007). The costs for screening are covered by the government; participation is voluntary. Each year approximately 1 million women are invited; about 80 percent accept the invitation (Oldenburg et al. 2007).

There seems to be a general agreement that – independent of whether a country offers a routine screening program or not – women should be properly informed about screening mammography, its advantages and disadvantages (Austoker 1999; Giordano et al. 2005) and the guidelines applied, especially with regard to the age group for which mammography is recommended. Several studies have examined predictors of women's adherence to mammography screening guidelines, including knowledge, attitudes, and beliefs about breast cancer and mammography (Vernon et al. 1990; Aiken et al. 1994; Skinner et al. 1998; Charnot & Perneger 2002).

Despite the extant empirical literature on breast cancer, few data are available on the level of women's knowledge of screening guidelines, on the factors influencing that knowledge and on the possible influence of this knowledge on behavior. The aims of this study are threefold: (1) to compare the knowledge of mammography screening recommendations of women in Lugano and Amsterdam; (2) to predict differences in knowledge of screening recommendations on the basis of a small set of variables like level of concern, media exposure, breast self-examination, and (3) to explore the relationship between knowledge of these guidelines and the intention to go or not to go for a mammogram.

2. Methods

2.1. Study Population

We studied 480 women in all, aged between 15 and 84: 240 in Lugano and Amsterdam each, from the beginning of June to the end of August 2007. Data collection was done by means of a short write-in questionnaire, consisting of not more than ten questions, handed over and collected personally. Trained female research assistants approached potential participants in front of several supermarkets, in Amsterdam also during travels by train. Participants were assured that their response would be confidential, and that completing the questionnaire would only take a

few minutes. After filling in the questionnaire, the women were debriefed about the aims of the research; if necessary for clarification of their written answers, a few oral questions were asked.

2.2. Measures

The questionnaire was designed to assess the knowledge of screening recommendations, information sources, and the awareness and concerns of breast cancer (see Appendix). As to general knowledge about screening, the respondents were asked whether they had ever heard that women above a certain age were invited every two years to go through a mammography. In case of an affirmative answer, we asked them above which age precisely women were supposed to undergo a mammogram (specific knowledge). As to the information sources, respondents had to indicate whether they accessed any of 7 sources of health information (i.e. exposure to television, print media, magazines, leaflets, relatives and friends, doctors, and unspecified sources).

The questionnaire sought also information on age and educational level. Furthermore, the participants had to answer questions concerning previous mammograms, intention to undergo a mammogram in the near future, former experiences with breast cancer among relatives, friends or colleagues, frequency of breast self-examination, as well as a question related to the level of concern in getting breast cancer.

Except for two (age; age above which women are supposed to go for a screening) all questions had precoded answer alternatives. A pretest among 14 individuals was run to determine whether the alternatives exhausted all the possible answers, and whether the questions were understandable to the lay public; some questions were modified slightly as a result of this exercise. In order to guarantee the compatibility of the questionnaire in Italian and in Dutch, the questionnaire items were first developed in English, and then translated into Italian and Dutch.

3. Results

In Lugano as well as in Amsterdam the response rate was very high: more than 90 % in Lugano and up to 95 % in Amsterdam. The vast majority of the women completed the questionnaire within a few minutes.

3.1. Socio-demographic Information

Socio-demographic information regarding the study samples is shown in Table 1. Age distribution is virtually the same in both samples (chi-square = 3.57; df = 2, p = .168), but they differ in educational level (chi-square = 54.81; df = 2, p < .001). In Lugano, more women were categorized in the lower educational levels, while in Amsterdam women were more often found in the higher educational levels.

3.2. General and Specific Knowledge of Screening Recommendations

The vast majority of the women in Lugano (95 %) as well as those in Amsterdam (90.8 %) answered in the affirmative when asked whether they had ever heard of a 'rule' that women above a certain age are supposed to have a mammography performed (see Table 2). This small difference in general knowledge of the screening recommendations between the two countries is not statistically reliable (chi-square = 3.17; df = 1, p = .075).

Table 1: Socio-demographic Characteristics of the Women (Age and Educational Level), by Country

	Study population				
	Lugano		*Amsterdam*		*P value*
	N	%	n	%	
Age (years)					*.168*
under 40	79	32.9	99	41.3	
40-49	54	22.5	47	19.6	
above 49	107	44.6	94	39.2	
Highest educational degree					*<.001*
Low level[1]	96	40.2	41	17.2	
Middle level[2]	110	46.0	100	41.8	
High level[3]	33	13.8	98	41.0	

[1] School with a nine-year programme
[2] School with a 13-year programme
[3] University or universities of applied sciences

However, while in Amsterdam 83.4 % of the women who had heard about the rule (n = 211) gave a correct answer to the question for what age group (i.e. above 50) mammography was recommended, only 25.1 % of the Lugano women (n = 219) gave a correct answer here. This tremendous difference in specific knowledge is highly significant (chi-square = 146.91; df = 1, p < .001). It cannot be explained by the observed differences in educational background between the two cities. First, if education were behind the difference in specific knowledge, one would expect a substantial increase in knowledge in both cities as the level of education gets higher – but that is definitely not the case (see Table 3): neither

Table 2: General and Specific Knowledge of Screening Recommendations, by Country

	Lugano	*Amsterdam*	*p-value*
	n (%)	n (%)	
General knowledge			
Yes	227 (95.0)	217 (90.8)	.075
No	12 (5.0)	22 (9.2)	(n=478)
Specific knowledge			
Correct	55 (25.1)	176 (83.4)	<.001
False	164 (74.9)	35 (16.6)	(n=430)

Table 3: Specific Knowledge of Screening Recommendations According to Different Educational Groups, by City

	Low EL		*Medium EL*		*High EL*	
	Lugano N=85 (39.0 %)	Amsterdam N=30 (14.3 %)	Lugano N=102 (46.8 %)	Amsterdam N=91 (43.3 %)	Lugano N=31 (14.2 %)	Amsterdam N=89 (42.4 %)
Correct	21 (24.7)	24 (80.0)	25 (24.5)	75 (82.4)	9 (29.0)	76 (85.4)
False	64 (75.3)	6 (20.0)	77 (75.5)	16 (17.6)	22 (71.1)	13 (14.6)

in Amsterdam nor in Lugano does there seem to be a substantial association between educational level and specific knowledge (chi-square in Amsterdam: .52; df = 2, p = .47; chi-square in Lugano: .28; df = 2, p = .59). Second, the results of an analysis of covariance equally run against the alternative explanation of an education effect. If one controls for the 'nuisance' source of variation due to the educational level, thus removing the effects of this variable (covariate) from the scores of the specific knowledge by means of an analysis of covariance, there still appears to be a highly significant difference in specific knowledge between the two countries ($F[1,425] = 183.35$; $p < .001$).

The superior specific knowledge of Amsterdam women could also be explained by differences in former experience with breast cancer among family, friends and colleagues. Although an association is observable between specific knowledge of the screening recommendations and experience, it does not appear to be significant (chi- square = 3.36; df = 1, p = .067) – at least not according to the conventional significance level of 0.05.

The difference in specific knowledge could also be explained by the fact that Dutch women over 50 are invited to mammography every other year, while Swiss women do not receive such an invitation. If the invitation improved knowledge, we would expect that knowledge is especially high in those groups who receive such an invitation, that is: Amsterdam women aged 50 and over. But no interaction between age and specific knowledge exists (see Table 4): The observed significant overall difference

Table 4: Specific Knowledge of Screening Recommendations According to Different Age Groups, by Country

	Below 40		*Age 40–49*		*Above 49*	
	Lugano N=71 (32.4%)	Amsterdam N=81 (38.4%)	Lugano N=50 (22.8%)	Amsterdam N=40 (19%)	Lugano N=98 (44.7%)	Amsterdam N=90 (42.7%)
Correct	12 (16.9)	55 (67.9)	12 (24.0)	32 (80)	31 (31.6)	89 (98.9)
False	59 (83.1)	26 (32.1)	38 (76.0)	8 (20)	67 (68.4)	1 (1.1)

in specific knowledge between the two cities is also found in each of three age groups (below 40 (chi-square = 39.92; df = 1, p < .001), between 40 and 49 (chi-square = 27.89; df = 1, p < .001), and above 49 (chi-square = 91.92; df = 1, p < .001). Notice that in the last age group only one out of 90 Amsterdam women gave a wrong answer, whereas 67 out of 98 Lugano women did that. The invitation sent out to Amsterdam women above 49 may therefore explain the difference in knowledge between the two samples for women in that age group, but it cannot directly explain the age differences between the younger groups.

3.3. Predicting Specific Knowledge of Screening Recommendations

In Table 5 data are presented regarding the remaining questions in the questionnaire – questions that, among others, will be used as predictors for the observed differences in specific knowledge of screening recommendations.

Lugano women are definitely much more concerned about breast cancer ("How often did you think of getting breast cancer the last two months?") than Amsterdam women (chi-square = 171.92; df = 2, p < .001); they are generally more exposed to information sources; they are much more willing to go for a mammogram ("Have you decided to go for a mammogram in the near future?") (chi-square = 169.56; df = 1, p < .001); they practice more breast self-examination ("How often have you checked your breasts the last two months?") (chi-square = 38.67; df = 2, p < .001) and they have had more mammograms in the past than the Amsterdam women ("Did you ever have a mammography?") (chi-square = 12.10; df = 1, p < .001). Only for the question "Do you have any experience with breast cancer among relatives, friends or colleagues?" do Amsterdam women give an affirmative answer more often than Lugano women (chi-square = 16.81; df = 1, p < .001).

For predicting the variability in specific knowledge of the screening recommendations, a discriminant analysis was run, with the following 16 predictors: (1) age, (2) educational level, (3) country, (4-10) the seven information sources, (11) level of concern, (12) former experience with breast cancer, (13) intention to go for a mammogram, (14) frequency of breast self-examination, (15) ever had a mammography, and (16) general

knowledge. The canonical discriminant function (n = 425 respondents) was highly significant (Wilks' Lambda = .58; chi-square = 227.99; df = 16, p < .001), leading to a correct classification of 80 % of all available cases

Table 5: Other Predictors of Specific Knowledge of Screening Recommendations, by Country

	Lugano	*Amsterdam*	*p-values*
Media Exposure			
High	134 (55.8)	46 (19.2)	< .001
Low	106 (44.2)	194 (80.8)	Chi-square 68.84, df = 1 (480)
Level of concern			
Low	45 (18.8)	188 (78.3)	< .001
Middle	163 (68.2)	38 (15.8)	
High	31 (13.0)	14 (5.8)	Chi-square 171.92, df = 2 (479)
Former experience with breast cancer			
Yes	112 (46.7)	156 (65.3)	< .001
No	128 (53.3)	83 (34.7)	Chi-square 16.82, df = 1 (479)
Intention to go for a mammogram			
Yes	167 (69.6)	27 (11.3)	< .001
No	73 (30.4)	213 (88.7)	Chi square 169.56, df = 1 (480)
Breast self-examination			
Once a week	83 (34.6)	31 (12.9)	< .001
Once a month	67 (27.9)	60 (25.0)	Chi square 38.67, df = 2 (480)
Less or never	90 (47.5)	149 (62.1)	
Ever had mammography			
Yes	130 (54.2)	92 (38.3)	.001
No	110 (45.8)	148 (61.7)	Chi square 12.10, df = 1 (480)

(i.e. the 425 cases with no missing values). The canonical correlation (i.e. the pmc between the binary criterion on the one hand and the whole set of predictors on the other) amounts to .65.

In order to get a more parsimonious prediction, we also ran a stepwise discriminant analysis (minimum partial F for a predictor to enter the function = 3.84; maximum partial F to remove a predictor = 2.71). Again we found a significant canonical discriminant function (Wilks' Lambda = .59; chi-square = 215.94; df = 4, $p < .001$), with a canonical correlation of .63, this time leading to a correct prediction of specific knowledge in 79.8 % of all available cases (n = 425) with only four predictors. In order of importance: city, age, intention to go for a mammogram, and least important: use of information from other sources. (The latter most often refers to the respondents' mother. When asked by the research assistants for a clarification of that rather vague option "other information sources," most of them referred to their own mother as the person who had informed them).

In view of all these statistics it can be argued that these four predictors are forecasting the criterion (specific knowledge of the screening recommendations) equally well as the 16 predictors in the analysis above. Being an inhabitant of Amsterdam, a higher age, an intention *not* to go for a mammogram and information from unspecified sources – in all likelihood the mother – are the factors responsible for a correct (prediction of) knowledge of screening recommendations in Lugano and Amsterdam.

Because of the comparative character of this study, we also analyzed, separately for the two amples, which variables predicted the knowledge of our respondents best. Using a stepwise analysis again, four predictors were able to classify 67.1 % of the respondents (n = 208) correctly in Amsterdam. In order of importance: age, level of education, general knowledge, and other information sources (i.e. the mother) (Wilks' Lambda = .81; chi-square = 42.33; df = 4, $p < .001$; canonical correlation: .43). In Lugano a comparable percentage (63.5 %) of the available cases (n = 217) was correctly classified on the basis of three predictors: age, information from doctors, and (in a negative sense) intention to go for a mammogram (Wilks' Lambda = .92; chi-square = 18.27; df = 3, $p < .001$; canonical correlation: .29). The prediction of the specific knowledge of screening recommendations is somewhat better in Amsterdam than in Lugano,

but – more important from a health communication perspective – the nature of these predictors is quite different for each of the investigated countries, except for the variable age.

3.4. The Relationship between Specific Knowledge and Proper Future Behavior

To get some more insight into the relationship between specific knowledge and proper future behavior, we once again ran a discriminant analysis with correct or incorrect intended future behavior regarding mammography as the binary criterion to be predicted. The future behavior in respect of mammography can be roughly classified as correct or false, at least according to the prevalent guidelines: respondents over 50 who intend to have a mammography and those under 50 who have no such plan intend to behave correctly; women under 50 intending to have a mammography and women over 50 with no such intention behave incorrectly. Of course, this criterion (correct or false future behavior) contains a certain amount of noise: for women below 50, for example, it is a reasoned choice to go for a mammography when breast cancer tends to run through her family. As a consequence, the prediction of this criterion will likewise be less than optimal.

In order to predict the proper future behavior of women, we created another new variable: actual proper (past) behavior, combining age and "Did you ever have a mammography?"(yes/no). Improper (past) behavior was for example ascribed to a woman below 50 who had already had a mammography performed. Notice that this variable is contaminated by a more or less equal amount of noise as proper future behavior.

Despite the noise in the predicted criterion, we were able, by means of a discriminant analysis, to predict the correct or incorrect behavioral intention of the women to a fair extent, namely in 84.3 % of the cases ($n = 381$) with the following predictors: (1) specific knowledge (2) information from health services, (3) information from leaflets, (4) information from newspapers and magazines, (5) information from other sources, (6) having had a mammography, (7) decided to have a mammography, (8) level of concern, and (9) actual proper (past) behavior (Wilks' Lambda = .731; $df = 9$, $p < .001$; canonical correlation = .52). Specific

knowledge of the screening recommendations thus seems to have some relation with women's proper behavior in the future.

A note of warning regarding the interpretation of these results is in place here. Due to the non-experimental, ex-post-facto nature of this research, it is quite difficult if not impossible to assign unequivocally a causal status to any of the used predictors.

4. Discussion

The differences found between the two cities, Amsterdam and Lugano, can be due to diverse factors. One is culture, with the Amsterdam data coming from a predominately protestant culture with Germanic roots, while the Lugano data originate in a mostly catholic culture in the Romanic part of Europe. A second group of factors may have to do with social structure: Amsterdam is a metropolis and the cultural center of its country, while Lugano is a comparably small city that may be central to Ticino, but rather of a marginal position for the country as a whole, Switzerland. A third cause of the differences between the two samples may be given by the different regulations for breast cancer screening, opportunistic in Lugano, and bi-annual invitation to mammography in the proper age group in all of the Netherlands. And finally, the different sampling frames (supermarkets in Lugano, supermarkets and trains in Amsterdam) cannot be completely excluded as a possible cause.

This is not the place to completely sort out these factors. Also, our data basis is not sufficient for that. We can, however, point out that other studies found knowledge levels for health-related matters rather low in Ticino, while care and health orientation and proper behavior were at levels comparable to other parts of Switzerland. One example is a study on organ donation in Switzerland (Schulz et al. 2006). The results demonstrate a need to consider and address cultural factors when designing organ donation campaign. More specifically, meanwhile for the Swiss-German subgroup information about organ donation and the procedures involved appeared to be very important, for the Swiss-Italian subgroup the social (local) contact played a most important role when it comes to the decision whether to sign an organ donor card. It is therefore likely that both the low level of knowledge of the proper age for regular examina-

tions for breast cancer and the high levels of concern, the high frequency of self-examination, the high willingness to have a mammography performed (in the past and in the future) and the high use of information sources. Or put in another way: Knowledge in the Swiss Italian culture of Ticino seems to be less related to information seeking, concern, care and prevention than elsewhere.

Conceding there are likely to be cultural causes to the differences we found, we will, howver, stress the role of the different regulations applied in the two cities. It is considered to be a truism that women should make their own reasoned choice based on sufficient information regarding the screening for breast cancer. From our study it may be inferred that the national program in Holland has at least one important consequence: Amsterdam women, mainly in the relevant age group over 49, are sufficiently well informed about the screening recommendations. In that age group only one out of 90 Amsterdam women gave a wrong answer, whereas in Lugano 67 out of 98 gave a false answer. The fact that younger age groups in Amsterdam seem also to be better informed even though the Lugano women claim to be more exposed to health information regarding breast cancer might be the result of a sort of diffusion effect: The older women who receive the invitation inform the younger (often their own daughters) about the proper age for mammography.

Another important result of our study is the finding that specific knowledge of the screening guidelines, indeed, does seem to play a role in women's proper decision whether to have a mammogram or not. According to this finding, the assumption of many information campaigns in the field of human health care that knowledge does affect behavior seems to be justified.

We also learn from our study that media exposure per se does not guarantee the required knowledge. Future communication to women should be tailored in terms of the relevant information given in the proper time.

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Appendix: Questionnaire

1. What is your age [numbers, not year of birth]
2. What is the highest school degree?
   [elementary school – university, including also: "not accomplished"]
3. Do you have children?
   Yes
   No
3. How many?
4. Did you ever hear that women above a certain age are invited every two year to go through a mammography, an x-rays photo of the breast?
   Yes
   No
5. If so, above which age?
6. Where did you get this information about mammography from?
   [several answers possible]
   Health services
   Special Leaflets
   Newspaper & Magazines
   Television
   Doctors?
   Friends?
   Colleagues?
   Others
7. Do your check your breast on a regular base?
   Yes
   No
8. If so, how many times in the past two months
   One time the week
   One time every two weeks
   One time every three weeks

Once the months
Less than once the month

9. Did you ever undergo a mammography?
   Yes
   No

10. Did you already decide to have a mammography in the next time?
    Yes
    No

11. Do you have any former experience with breast cancer among relatives, friends or colleagues?
    Yes
    No

12. In the last two months, how often did you think about getting breast cancer?
    One time the week
    One time every two weeks
    One time every three weeks
    Once the months
    Less than once the month