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RESEARCH ARTICLE

KNOWLEDGE, SCREENING HISTORY AND SATISFACTION AMONG ELIGIBLE FOR CANCER SCREENING PEOPLE IN BULGARIA.

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Abstract

Cancer screening is one of the instruments for cancer control. The introduction of population-based screening programs can lead to a significant reduction of mortality and morbidity, if quality criteria are met. In Bulgaria, screening is opportunistic, unsystematic and ineffective.

Aim: To study the information level, the experience and the attitudes of eligible for cervical, breast and colorectal cancer screening people in Bulgaria.

Methods: 256 women and 44 men were divided into three groups and interviewed for a particular screening site. The age range of each group was in accordance with the European and national recommendations. The data were collected in May 2018 through standardized interviews at the respondents' home.

Results: The knowledge about screening tests among citizens is insufficient and varies in regard to different cancer sites. Information on aims, eligibility, screening intervals and follow-up is not consistent and often insufficient. Positive attitudes to screening prevail, with the recommendation given from a doctor being preferred to the written invitation.

Conclusion: Continuous efforts are needed to raise the information level and knowledge about screening, its nature and objectives. Due to the efforts in the last decade, improvement is visible in regard to information and practices of cervical cancer screening. Brest and especially colorectal screening are less popular in the country. It is necessary to develop algorithms and guidelines for medical professionals conducting screening, as well as unified documentation.

Introduction:-

Cancer is one of the most serious public health issues and concerns that yearly causes millions of deaths worldwide. Cancer incidence and mortality are rapidly growing (Bray et al. 2018).There is enough evidence that a big proportion of cancer deaths could be avoided through individual and group preventive actions. Population-based screening programs for breast, cervical and colorectal cancer could help significantly for reducing the incidence (of cervical and colorectal cancers) and mortality from each of these three cancer sites.

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Although there are clear instructions on screening implementation (Council Recommendation 2003), considerable disparities still exist between the European Member States in terms of the status of implementation and the extent to which screening programs are organized. Even in countries with well-organized screening services, these benefits are not enough maximized in underserved or uninsured populations due to different factors such as access difficulties, discomfort with the screening procedure, insufficient health literacy, additional costs and others. In Eastern Europe cervical cancer is still a considerable public health problem with high cancer incidence and low rates of screening participation (Arbyn et al. 2011) (Cancer screening in the European Union 2017)

The political and economic changes in Bulgaria during the transition after 1990, have created greater disparities in access to screening (Todorova et al. 2009). People are facing structural and personal barriers, which are limiting motivation, access and uptake. Existing barriers are usually connected with the organization of the healthcare system, the doctor-patient relationship, as well as psychosocial factors, such as perceived stress and social support (Avramova et al., 2005).

Although there were many initiatives and attempts for improvement throughout the years, Bulgaria is still among the European countries with no organized screening program for any site. Opportunistic screening is available on paper, but in fact not all people who would like to be screened, may get it. There are serious disparities across the country, based on social, ethnic or educational differences.

First attempt for implementation of a screening program in Bulgaria was in the 1970s with the cervical cancer. Screening was organized at work places, women were obliged to participate and for the period between 1970-1985 cervical cancer incidence and mortality rates remained relatively stable. However, there were a lot of problematic organizational issues during this program, as well as improper quality control (Zlatkov&Kostova-Zlatkova 2006).

The only national-wide effort for implementation of the population-based model was between 2009 and 2013 with the pilot project 'Stop and Get Screened', organized by the Bulgarian Ministry of Health and implemented with the financial support of the European Social Fund. Its aim was to build up the organizational model for breast, cervical and colorectal cancer screening, using the population-based approach. During the project, the National Screening Registry was established, a call-recall system was set-up and a national information campaign was conducted. The uptake was low but comparable with the uptake in other Eastern European countries in their first rounds.

Together with it gains, this project had also many restrictions. Firstly, it couldn't explain clearly its aims to the general public. There was no need assessment study prior the beginning of the project, in order to get better information on motivations and barriers of people. Secondly, for some reasons, general practitioners were excluded from the project. They were neither informed who were the invited people from their lists, nor if these people were screened and what were their results. Thirdly, follow-up was not included in the project at all. Another problem was the lack of assessment of human and physical resources – it was not clear if there were enough specialists to perform screening testing and also if there is enough capacity in the facilities. And finally, there were no clear conclusions and recommendations neither for health authorities, nor for the general public following this project. So, the main aim of a pilot project – to test a population-based screening model and to give clear recommendations for improvement was just partly fulfilled.

An essential part of any screening strategy is the assessment of the willingness of people to get screened and the barriers to this choice (Todorova et al. 2009), (Craciun et al. 2018). Knowing factors that hamper citizens in taking a decision to go for screening, can help in the development of activities and materials to facilitate their choice and help to improve recall when invited (Gergov 2016); (Dimova R, Dimov R., 2007); (Dzafer 2015). Previous study on cervical cancer screening in Bulgaria concludes that women who took the initiative for smear taking face fewer health system related and personal barriers. These women usually have a greater degree of knowledge about cervical cancer, are less likely to assess the gynecological visit as unpleasant and rarely find difficulties in communication with providers (Avramova 2005; Todorova et al. 2009).

The balance between perceived psychosocial barriers and facilitating factors prompts individuals to form a strong intention and then to act upon the intention. Perceived barriers may refer to individual, social or environmental characteristics (Tanner-Smith & Brown 2010). Building health care systems that can address multiple factors simultaneously, would improve cancer screening rates and overall outcomes for populations.

Among the factors defining attitudes to regular screening is the overall satisfaction with screening services, including specific assessment of the level of discomfort, concerns, and feelings of personal effectiveness or obligation to participate among men and women who got screened (Peipins et al., 2006); (Tang et al., 2009). Peipins et al. found that satisfied women tend to participate more in future screening examinations The elements of satisfaction are: service accessibility, information provided before testing, physical discomfort and/or pain, anxiety, staff communication skills, physical conditions (environment, equipment), results communication etc. Understanding the general and specific determinants of satisfaction allows identifying and solving problems, which in turn can lead to improvement of services. This is particularly important in national organized programs, where high quality should be maintained for a long time in all screening units and for all strata of the population (Gabel et al. 2017), (Almog et al., 2008).

The results of the cross-sectional study, conducted in Denmark, reveal very high satisfaction with the breast cancer screening program. However, satisfaction was lower among women who felt discomfort during the screening examination, felt obliged to participate, or experienced screening-induced concerns. Lower satisfaction was also reported by older women, non-western immigrants, and women with low education levels (Gabel et al., 2017).

Obligation to participate in a screening program, could be institutional or interpersonal. The concept of moral obligation in relation to cervical, breast and colorectal cancer screening has been studied in different contexts (Bush 2000), (McAlearney et al. 2012), (Tacken et al. 2007), (Griffiths et al. 2010), (Ward et al. 2015).Different researchers found that obligation was a key factor in determining patient uptake (Howell and Shepper 2013), (Torke et al. 2013). Data shows that some people participate in screening programs regardless of their level of knowledge and not through their active choice but through a perceived obligation to healthcare professionals and the healthcare system more broadly.

The **aim** of the current research was to study the information level, the experience and the attitudes of eligible for cervical, breast and colorectal cancerscreening people in Bulgaria.

Methodology:-

Data Collection:-

The study involved 256 women and 44 men. Participants were divided into three groups and interviewed for a particular screening site. Men were about half of the subjects in the colorectal cancer study. The age range of each group was in accordance with the European and national recommendations, as follows - 25-59 for cervical, 45-69 for mammography and over 50 years for colorectal screening. One hundred representatives for each group were selected by age, place of residence, education and ethnicity. The sample includes residents of Sofia, Bourgas, Pleven, Pernik and Stara Zagora) as well as of villages in the regions of Pernik and Pleven.

Data were collected in May 2018 through face-to-face structured interviews in privacy at the respondent's homes by a network of trained interviewers. The structured interviews were conducted after explanation about the aim and procedure to every participant and her/his consent to participate.

A structured questionnaire was developed, informed by existing methodologies in the field. It contained the following sections, relevant for this Paper.

1. Demographic characteristics of participants included age, education, marital status, ethnicity, religion, and place of residence.
2. Knowledge: six items regarding participants' knowledge about the nature and purpose of screening tests.
3. Pastscreening history:-six items regarding being tested in the past, initiative, refusals and reasons for them, abnormal results and follow-up.
4. Perceived barriers:-based on the literature and on the questionnaire of a previous study, conducted in the country (Avramova et al. 2005).
5. Satisfaction:-a scale, adapted from a questionnaire, applied in Denmark for breast screening, including questions on overall satisfaction, discomfort and/or pain during screening and specific concerns (Gabel et al, 2017).
6. Attitudes toward screening:-four items on readiness to be tested if invited by health provider or written invitation, and personal reasons to be screened.

The data were analyzed using the Statistical Package for the Social Sciences (SPSS) by conducting descriptive statistics, ANOVA for comparison of means, and Chi-square for comparison of proportions.

Results:-

Sample Characteristics:-

According to their place of residence, more than half of the participants were living in the capital of Sofia (58.33%), about one third in district towns (33%) and about one quarter lived in villages (25%). Over two thirds of the participants were living in a marriage or cohabitation, and about a quarter were single, divorced or widowed. The reported ethnicity of the respondents was predominantly Bulgarian, with about eight per cent who self-identified themselves as persons of Turkish or Roma ethnicity. According to their level of education, about half of the participants had secondary education and one third - higher education. The rest had lower than secondary or no education. More than ten per cent of the respondents were unemployed during the survey period, about two thirds - employees and over twenty percent - retired.

Knowledge and Information:-

The comparison of the information level regarding three cancer sites shows better awareness about cervical cancer. Almost all respondents have heard the term "PAP smear" (93%), while for mammography about 86 % were sure or with some level of certainty, and for the faecal blood test -71%. The distribution of people who have certainly heard about the tests was 93% for Pap smear, 71% for mammography and 25% for FOBT.

Answers regarding the purpose of the screening tests show that less than a half of the women know the exact purpose of the smear test, namely to discover changes in cervical cells. About one third of them were thinking that the aim of the test is to detect infections in the woman's vagina, another 13% - to discover changes in female genitalia, and 7% did not know. According to 45% of those,asked for breast screening, the aim of mamography is to "find lumps", another 24% thought it detects changes in tissues or benign changes, 14% - that it detects cancer, and 17% didn't know. Among the participants asked about colorectal screening, 39% said that the goal of the FOBT is to detect infections in the colon or/and the rectum, 15% said that the goal is to detect cell changes, 22% - that the aim is to identify polyps or other changes in the bowel, and 24% did not know.

Study results show that most of participants believed that screening test should be performed when symptoms as pain, bleeding or leakage are available. Just about one-third of respondents for cervical cancer and one fifth of people asked about mammography and the faecal blood test responded that these tests should be part of preventive check-ups. Others had no answer. No one from the participants of Roma ethnicity pointed out prevention as an aim of screening.

Another issue in the study regarding knowledge and information was participants' awareness on preventive 'power' of screening. And again, women asked about Pap smears were better informed than the other respondents. Good information level was shown also in regard to mammography screening – one quarter of respondents believe that it could find breast cancer in an earlier stage, when the prognosis is good. Taking into account that this answer is also relevant, it could be said that more than two thirds of participating women were well informed about the strengths of mammography screening.

Table 1:-Answers about the potential of screening tests to prevent cancer

Answer	Pap smear, N	Mammography, N	FOBT, N
Yes	71	44	32
No	11	17	46
Early detection	-	25	-
Don't know	17	14	21
Other	1	-	-
Total	100	100	99

One of the criteria for evaluation of screening services is the quality of the provided before the procedure information. Asked whether they received information from the medical staff about the nature, benefits and risks of the procedure, less than half of the respondents answered affirmatively. Of these, the largest proportion of positive responses were given for Pap smear (70%), followed by mammography (48%), and only one in ten respondents - for

FOBT. It is noteworthy that the number of respondents, who gave no answer or "I don't know", exceeds the number of positive answers.

In addition, data on informed consent or other documents, accompanying screening examination, shows that about half of respondents did not sign any document, informing them about the objectives and risks of the examination. Less than 10 per cent responded positively. Answers about how participants in the study received their test results were also concerning. Only about half of respondents had received their results from their GP or other medical staff. The rest, either did not receive them or did not answer the question. A good indicator is that the ones who've got their results stated they have discussed them with a nurse or a physician.

Screening History, Barriers and Satisfaction:-

Screening history of the participants was studied by questions on if participants were ever tested, whose was the initiative for testing, if they ever had a refusal to be tested, if they ever had abnormal results and on the follow-up.

Table 2:-Screening history (Have you ever had a screening test?)

	PAP smear, N	**Mammography, N**	**FOBT, N**
Yes	88	52	12
No	10	34	59
Not sure	1	7	14
Don't know	1	6	15
Total	100	99	100

Results show that most of women, asked about smear test, half of those asked about mammography and very few of people, asked about. FOBT had it at least once in their lives (Table 2).

Regarding initiative for testing, data shows that most often it comes from medical providers – GPs or specialists. One quarter of women participating in the study on cervical cancer had initiated themselves check-up, including smear testing. In the breast cancer part - about 15 % took initiative for mammography. Deeper look at demographic characteristics of participants shows that women who took initiative to be screened were predominantly of Bulgarian ethnicity, well-educated and employed.

The last section of the study on screening history refers to the probability and reasons for medical providers to refuse screening to people who search preventive check-ups and testing. Data shows that refusals were quite rare. However, most often women get refusals for mammography - about 20 percent of respondents got it at least once. There was no connection between refusals and place of residence, educational level or ethnicity. The most often pointed reasons for refusal were the lack of (enough) available to providers referrals, and physicians opinion that the person is healthy and the test is not necessary to be performed.

Perceived barriers:-

Table 3:-Perceived barriers to screening.

Answer	**Pap smear N**	**Mammography N**	**FOBT N**	**Total, N**	**Total, %**
Lack of time	7	11	13	**31**	**7.36**
My doctor never offer	20	9	35	**64**	**15.20**
I don't know to whom to refer and what the procedure is.	1	21	15	**37**	**8.79**
Visits are unpleasant	24	2	25	**51**	**12.11**
Fear of bad diagnosis	11	12	12	**35**	**8.31**
High costs	3	9	6	**18**	**4.27**
I don't think that doctor would pay attention to me if I go just for screening.	3	14	25	**32**	**7.60**
I am healthy and don't need it	34	14	33	**81**	**19.23**
I did not delay it	16	6	5	**27**	**6.41**
No reason to delay	1	8	-	**9**	**2.13**

Other	1	19	1	**21**	**4.99**
Missing	2	1	2	**5**	**1.19**
Total	123	126	172	**421**	**97.59**

Perceived barriers of respondents to delay screening are presented on Table 3.

The responses show that the lack of symptoms, i.e. the "I'm healthy" self-esteem was the most common reason for postponing screening, followed by the lack of suggestion from a doctor. Important systemic barriers were the neglect and underestimation of preventive check-ups by GPs, not covered by insurance costs and others. Significant personal barriers were also the unpleasant feelings, fear of a poor diagnosis, the expectation that the doctor won't pay attention, the lack of time, and so on. It is interesting to note that the largest number of answers "I do not know to whom to refer" were given by women, asked about breast cancer, followed by those, asked for colorectal cancer, while only one woman gave this answer for cervical smear.

The feeling that the check-up is unpleasant is a significant barrier for respondents about breast and colorectal screening, but not for cervical. Of all respondents in breast cancer survey, just 2 women evaluated the discomfort during the examination as significant or to some extent. Similarly, only two women identified the pain as essential and felt that their personal limits of modesty were exceeded. On the other hand, in the sample on cervical cancer, about half of women reported pain experience, one quarter reported discomfort during the examination and one in ten - a feeling of violation of the personal limits of modesty.

Satisfaction:-

The overall impression of the cervices, received during the screening examination, is positive. Although about half of the respondents did not answer the question on overall evaluation, the ones who gave answer, rate the received services as good or very good. Among people, who did not reply, the largest proportion was about faecal blood test (more than 85%). This data reflects the number of people who have ever been tested. There were just few (N=7) people, who gave excellent evaluation to the received services and six of them – about smear taking.

Satisfaction with the services could be indirectly measured through the willingness of already screened people to do their next examination at the same setting and with the same physician (if possible). The results show that more than two-thirds (80%) of participants would return at the same screening unit and to the same doctor. It is noteworthy to say, that in Bulgaria all screening tests are performed mainly by physicians, especially the Pap smears. The role of nurses is still undermined.

Attitudes to Participation in the Future:-

Willingness to be screened:-

Attitudes towards screening were studied, using questions whether participants would go for check-up if get invitation – by mail or from physician. In both cases positive attitudes were prevailing, with differences between invitation approach and between the three groups of respondents. More than 75% would go for screening, if referred by their GP or other medical specialist, while 63% would go after receiving mailed invitation. Most of participants who would go for screening if being referred or invited, would go for Pap smear, following by those for mammography and faecal blood test. From those who were not sure whether would go or not, more people would potentially neglect written invitation (N=87) than referral from a physician (N=51).

Feeling of Obligation:-

Among the main reasons, that make people to go for screening, if invited were their knowledge that screening test might save their lives if changes are detected early enough, the understanding that their family would appreciate it and the opportunity to get free of charge testing. Results are presented on Table 4.

Table 4:-Reasons to feel obliged to participate in cancer screening.

	Pap smear, N	**Mammography, N**	**FOBT, N**	**Total, N**
Early detection might save my life	74	54	43	171
My family would like me to get screened	6	22	15	43
Invitation gives opportunity for	17	19	35	71

free of charge examination				
Other	2	2	3	6
Total	99	97	96	292

Discussion:-

Knowledge about cervical cancer and cervical smears is an important determinant of both past screening history and future screening intentions. Our data confirms the existence of varying levels of knowledge on breast, cervical and colorectal cancers, and the screening process.This study shows that in Bulgaria, in the last two decades awareness about cervical cancer arose significantly. In the current study almost all respondents have heard the term "Pap smear" and about 90 % of participated women had smear test at least once in their lives. To compare, in the representative study, conducted in 2004, about half of respondents didn't know about cervical smears and never had been tested (Avramova et al. 2005), (Todorova et al. 2009). The study of 2004 found also that Bulgarian women who "were in the younger age group, who were single, who were of ethnic minorities, living in smaller villages and towns, having fewer years of education and lower financial resources were significantly less likely to have had a smear"(Todorova et al. 2009). The current study did not find so deep inequalities in regard to cervical smears.

This study shows insufficient knowledge on the aim and nature of all screening tests. Although respondents were quite well-informed about age intervals for each test, most of them thought that they should be applied in case of symptoms (pain, bleeding or leakage) and not as a preventive ones.

For the quality of the screening services, of greater importance is the information provided within the program, opportunity for informed choice and user-friendly reporting of results. The obtained data in this regard are worrying as they show that the information provided by the most trusted source of information – health providers, is insufficient. It is noteworthy that about half of the women undergone mammography were not informed about the examination. Given its specificity, the fact that it is associated with exposure to radiation and often with discomfort, the guidelines of good medical practice in screening indicate that women should be clearly informed about the benefits and possible risks of mammography, including the quality of the used equipment, exposure levels, etc.

The comparison of the data on providers' refusal to refer for cervical screening test shows an increased number of refusals in 2018 compared to 2004. In the 2004 study, less than 2% of participants gave a positive answer to the question if they had ever been denied a Pap smear while in 2018 they were about 8%. These data should be proven through further investigations.

Perceived barriers are also changing with time. Comparison of data in regard to cervical cancer screening shows that while in 2004 the main barriers were:l ack of suggestions by the health providers, fear of poor diagnosis and the feeling that doctor would neglect their request, in 2018 the main perceived barrier was the feeling of being healthy and understanding that going for check-up was needless.

As a whole, it could be said that there is enough positive attitude for screening among Bulgarian people. However, the invitation process should be refined, taking into account people's preferences for referral from health specialist instead of anonymous invitation from a health institution.

Conclusion:-

There is insufficient public information on cancer screening in the country. Eligible people are not enough aware on available screening tests, their rights to use them free of charge and the aim of each test. People should be provided with enough information and documentation on screening in order to take their informed decision. Health providers are still the most reliable source of information and advice. Excluding general practitioners from the screening process is a poor practice that has to be rapidly overcome.

The tendency for not enough referrals for prevention is still existing in the country. Social and economic disparities are still at place but gradually overcome.

Although in Bulgaria population based screening programs are not available and there are not unified criteria for quality assurance, there is a growing amount of studies, trying to assess situation and give proposals for improvement. Information campaigns preceding or accompanying screening activities should be in accordance to

the demographic characteristics of the eligible populations. National information campaigns are not always the best choice, being expensive but not necessarily effective. Using different approaches as regional media, educational initiatives and health mediators could significantly improve information level and attitudes towards cancer screening.

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