



## Health education for early detection of breast cancer in blind women

Educação em saúde para detecção precoce do câncer mamário em mulheres cegas

Educación en salud para detección precoz del cáncer de mama en mujeres ciegas

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**Objective:** to assess the knowledge of blind women about the risk factors for breast cancer and whether they look for early detection of this cancer. **Methods:** a quasi-experimental study with 72 blind women distributed in focus groups. Data were collected through interviews. **Results:** few participants had knowledge about one or more risk factors for breast cancer, but most practiced early detection. Health education was developed using breast kits and demonstration of breast self-examination. It was obtained qualitative improvement of knowledge of the participants about breast cancer, its risk factors and early detection practices. In addition, participants demonstrated breast self-examination confidently. **Conclusion:** we need to develop in a harder manner educational activities to clarify about breast cancer risk factors and the importance of periodically carrying out breast self-examination, clinical examination and mammography.

**Descriptors:** Nursing; Health Education; Breast Neoplasms.

**Objetivo:** averiguar o conhecimento de mulheres cegas sobre os fatores de risco para o câncer mamário e se elas buscam a detecção precoce dessa neoplasia. **Métodos:** estudo quase-experimental com 72 mulheres cegas distribuídas em grupos focais. Coletaram-se dados por meio de entrevista. **Resultados:** poucas participantes conheciam um ou mais fator de risco para câncer mamário, mas a maioria pratica a detecção precoce. Desenvolveu-se educação em saúde utilizando kits de mama, demonstração do autoexame da mama. Obteve-se melhora qualitativa do conhecimento das participantes sobre o câncer mamário, seus fatores de risco e as práticas de detecção precoce, além das participantes demonstrarem, com segurança, o autoexame da mama. **Conclusão:** é preciso desenvolver, com mais afinco, ações educativas que esclareçam acerca do câncer de mama, dos fatores de risco e da importância de se realizar, periodicamente, autoexame das mamas, exame clínico e mamografia.

**Descritores:** Enfermagem; Educação em Saúde; Neoplasias da Mama;

**Objetivo:** evaluar el conocimiento de mujeres ciegas sobre los factores de riesgo para el cáncer de mama y se ellas buscan la detección precoz de este cáncer. **Métodos:** estudio cuasi-experimental con 72 mujeres ciegas distribuidos en grupos de enfoque. Datos recolectados a través de entrevistas. **Resultados:** pocas participantes conocían uno o más factores de riesgo para el cáncer de mama, pero la mayoría practicaba la detección temprana. Educación para la salud se desarrolla utilizándose kits de mama, demostración del autoexamen de mama. Se obtuvo mejora cualitativa del conocimiento de las participantes sobre el cáncer de mama, sus factores de riesgo y las prácticas de detección precoz, además de las participantes demostrar, con seguridad, el autoexamen de la mama. **Conclusión:** es preciso en profundidad desarrollar actividades educativas acerca del cáncer de mama, los factores de riesgo y la importancia de realizar periódicamente el autoexamen de las mamas, examen clínico y mamografía.

**Descriptores:** Enfermería; Educación en Salud; Neoplasias de la Mama.

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## Introduction

Breast cancer is a disease characterized by cell proliferation in breast lobules and ducts, whose most common manifestation is the appearance of painless, hard and uneven lump, but there are tumors that are soft consistency, globular and well defined. In Brazil, the incidence of this cancer is higher among women, accounting for 22.0% of new cases each year. In this sense, estimates for the biennium 2014-2015 indicate the occurrence of approximately 57,000 new cases of the disease, with an estimated risk of 56 cases per 100,000 women<sup>(1)</sup>.

The risk factors for this type of cancer are the following order: female gender, age, with increased incidence up to 50 years old, early menarche, late menopause, nulliparity, late or early maternal age at first pregnancy, abortion, prolonged use of oral contraceptives, use of hormone replacement therapy, personal history of benign proliferative breast disease; exposure to ionizing radiation between puberty and 30 years of age, changes in some genes such as BRCA1 and BRCA2, family history of cancer, obesity, alcohol intake, physical inactivity, absence or short periods of breastfeeding and smoking<sup>(1)</sup>.

Despite these multiple risk factors, it is possible to slow down and even prevent this neoplasm in one-third of the affected or vulnerable population, annually, provided there is effective and efficient control of these factors. Accordingly, the mammographic screening and health education are the optimal strategies for early detection of breast cancer. These procedures, besides contributing to treatment at the stage where the tumor is located, enable increased survival of people subjected to therapy<sup>(2)</sup>.

In the case of health education, it enables the construction of knowledge through dialogue between scientific knowledge and that of common sense<sup>(3)</sup>. Among other possibilities, this benefit can be achieved with the implementation of a health education clinic with services provided by nurses, aiming at guidance and monitoring of patients and family service users, in

different clinical areas<sup>(4)</sup>.

The idea of health education clinic refers to the question: how does the practice of educational activities occur in primary care? The literature answers to this question by stating that primary care nurses practice educational activities in different ways: some give primacy for dialogued, reflective and problem-solving actions, whereas others transfer information, reproducing the depositary pedagogical model that does not match emancipatory health education<sup>(5)</sup>.

This statement is of greatest concern when directed to the group of disabled people, as there are already authors reporting about the challenges to the construction of solidary, embracing and more effective and resolving health practices to these subjects. Among the difficulties, it is mentioned: disarticulation between primary care teams and those of medium to high complex services, insufficient community health workers, professionals without training to assist the disabled, repressed demand, long term medical appointment scheduling, time-consuming additional examinations and of questionable quality, lack of plans, programs, projects and/or continuous actions to care for the individual<sup>(6)</sup>.

In the context of this order, it can be inferred that blind women do not receive fair health education to enable them for self-care. And in the case of early detection of breast cancer, it is worth asking: what do blind women know about breast cancer? Do they practice the early detection of breast cancer?

It is believed that these women, when compared to those non-blinded, face some difficulty to examine their bodies in search for signs of such a specific grievance as breast cancer. And considering the difficulties already mentioned and of which the Family Basic Health Units teams suffer, authors sought to investigate the knowledge of blind women about the risk factors for breast cancer and whether they look for early detection of this cancer.

The results of this study will bring benefits to the population group involved, given that health education activities will seek to replace common

sense knowledge about breast cancer by academic knowledge on the etiology and early detection procedures of this neoplasm.

This study is important because it can contribute to the strengthening of information/communication systems about the health education of the disabled. Also because it is estimated that its results will provide to health managers information for planning and implementing health education strategies aimed at the precocity of the detection, assessment, treatment and rehabilitation of blind people, vulnerable or affected by this disease.

Finally, the results will represent a portion of return, through which the academy seeks to fulfill its social function of transforming and improving the health of different social segments.

## Method

This is a descriptive study of qualitative approach, carried out from 2012 to 2014, in Family Basic Health Units of the Micro-region of Agreste da Borborema, one of the seven regions forming the Compartment of Borborema, in the rural region of the state of Paraíba, Brazil. This micro-region consists of 12 cities and, among these, six were selected for the study. The research was developed in four stages:

Step 1 - Pact with the Primary Care Management, determining that the activities would take place in the days established by each Family Basic Health Unit, according to service availability. Survey of the number of blind women, with the support of Community Health Workers. Home visits to blind women to present the researchers, objectives, benefits and possible risks of the research. When the invitation to participate in the research was accepted, the Informed Consent Form was signed in duplicate; a copy stayed with the participant and the other with researchers. When the participant could not read or use a Braille slate, they used the fingerprint of the right thumb. Then, researchers scheduled for the participant to attend in the Family Basic Health Unit for data collection.

In the selection of participants, the age group was prioritized, according to the National Program for Breast Cancer Control, which recommends for the start of the routine of clinical examination of the breasts and mammography from age 35, in addition to presenting preserved cognitive function and living in urban areas.

A total of 72 women were selected by convenience. Six focus groups were formed, one in each city and each group with 12 participants. On the occasion of the home visit, it was clarified that in the first meeting with each group individual interviews would be performed aiming to collect data to conduct educational activities in the following meetings, and the fellowship of the group.

Step 2 - Semi-structured interview on sociodemographic profile, knowledge about breast cancer, risk factors associated with this cancer and early detection practices. The interviews took place individually, with the presence only of researcher and participant. They lasted on average 20 minutes and were recorded. Each recording was identified with a pseudonym. Then, the content of the interview was played back so that participants could validate their speeches.

Step 3 - Development of the Focus Group, whose activities took place in environment offered by the Family Basic Health Units once a week for two hours in a consensual day to researchers and participants.

An interviewer, a moderator and an observer participated in each Focus Group. There were six meetings with each group, and the following activities were implemented: 1) Discussion on the genesis of breast cancer and risk factors. 2) Handling, by participants, of kits with breasts models, each containing a normal breast and two with various types of nodes and changes of skin and breast form, for identification, by palpation, of normal breast and those with abnormalities. 3 and 4) Guidance to participants on how to perform breast self-examination, with women in positions: sitting, while bathing and lying. 5) Participants demonstrated how to do the breast

self-examination. In all meetings, discussions were recorded and closed at the time that no more groups presented new data on the subject under study. 6) Reapplication of the Phase 2 instrument.

Step 4 - Six months after the completion of the Focus Group, researchers proceeded to evaluate the educational intervention. On scheduled days with all participants, researchers presented the consensus of these groups to be validated. Then, the initial findings were compared with the results of the educational intervention.

As for analysis, the data obtained from the interviews were transcribed and submitted to descriptive statistics and to thematic content analysis, as the steps: Reading the material to know the text; Coding and identification of record units; Grouping of record units with the same meaning; Thematic categorization in accordance with the meaning included in the record units grouping; Treatment of results, inference and interpretation<sup>(7)</sup>.

From this analysis, five thematic categories emerged, whose speech clippings were compared with the recommendations of the National Program for Breast Cancer Control for cutout of information lacking professional guidance.

It was also conducted the thematic content analysis<sup>(7)</sup> of data obtained in the educational activity. Results of analyses of interviews were compared with the results of the educational intervention to evaluate the acquisition of new knowledge and behavioral change in relation to the early detection of breast cancer. Final results of the study were presented in tables and figures.

The project was submitted to the Ethics Research Committee of the State University of Paraiba, approved under opinion No. 0070.0.133.000-09. The proposed ethical guidelines for research with human beings were respected. The selected participants signed the Informed Consent Form. Each participant received an alias to ensure the confidentiality of answers to questionnaires.

## Results

Activities developed in this study allowed obtaining data that supported the development of educational activities aimed at demystifying wrong knowledge about breast cancer and sharing the knowledge released by the National Cancer Institute about this neoplasm. The assiduous frequency of participants in all meetings scheduled with researchers was remarkable.

**Table 1** - Sociodemographic profile of participants

Variables	n(%)
Age group (in years)	
35 - 39	11(15.0)
40 - 49	17(24.0)
50 - 69	28(39.0)
>70	16(22.0)
Education	
Illiterate	21(29.0)
Complete Elementary School	15(21.0)
Complete Secondary School	18(25)
Complete High School	13(18.0)
Complete Higher Education	5(7.0)
Marital Status	
Single	39(54.0)
Married	28(39.0)
Widow	5(7.0)

In Table 1, it is emphasized that 56 (78.0%) participants have age consistent with that considered by the National Cancer Institute as a priority for the screening of breast cancer, i.e., women aged from 35 to 69 years old; 51 (71.0%) have education from complete elementary school to complete higher education. In the case of the 21 (29.0%) illiterate participants, this situation occurred in those aged 50-69 years old and those aged 70 years old and older; 33 (46.0%) have or had a partner.

**Table 2** - Knowledge of participants about the risk factors for breast cancer

Information from participants	Know n(%)	Do not know n(%)
Internal causes		
Heredity	17(24.0)	55(76.0)
Uncontrolled hormones	54(75.0)	18(25.0)
Having more than 40 years of age	64(89.0)	8(11.0)
External causes		
Breastfeeding for a short period of time	55(76.0)	17(24.0)
Red meat consumption	58(81.0)	14(19.0)
Smoking	13(18.0)	59(82.0)
Alcohol consumption	13(18.0)	59(82.0)
Trauma	51(71.0)	21(29.0)

Table 2 stands out that 55 (76.0) participants were unaware of heredity as a risk factor for breast cancer. In this study, 18 (25.0%) participants reported receiving nursing guidance on the subject. The others (75.0%) reported having obtained knowledge by the media.

Interview data originated the themes that are presented in Figure 1 below:

The comparison of results obtained from interviews in Step 2 with the results obtained with the educational intervention showed qualitative change in the knowledge of participants, such as shown in Figure 2.

Thematic categories	Recording units (Meaning Cores)
What blind women want to know about breast cancer	<i>I always kept thinking: this disease appears suddenly. How does this disease start? (Alda). You know, since I feel nothing, I never looked for a doctor. So I cannot tell you (Marta).</i>
Knowledge of blind women about the risk factors for breast cancer	<i>Well, I know that if you have someone in the family who had this problem, other relatives may also have it (Zaira). Smoking, drinking and other things that happen in humans may cause this disease (Socorro).</i>
Knowledge of blind women about early detection of breast cancer	<i>This is easy. Just do breast examination and examination of the cervix (Valéria). To prevent it, you need to do that examination by raising the arm and with your right hand you examine below the armpit, and then the other the same way, in the bath and laid (Elen). It happens if someone breastfeeds too much and smokes. It happens to women who have uncontrolled hormones, uncontrolled bleeding, hereditary factor. This disease depends on the woman having a family history, not seeing a doctor (Vivian).</i>
What blind women want to learn to early detect breast cancer	<i>I want to learn the touch examination, among other information. I want to know how to make the detection to protect me (Eliete). The other day the doctor said that the person can do the breast examination at home. I want to learn how to do it (Cícera).</i>
Resistance practices of blind women in relation to knowledge about breast cancer and early detection of this disease	<i>I do not want to learn anything. I just want to look. I'd rather not knowing (Nora). I do not want to learn anything, because I'm afraid to find something, I'm afraid to go to the doctor (Linda). No, no, I do not want to know about lump, no. I am afraid of tearing my breast. Yeah, I do not (Carol). I do not want to learn. I'm afraid of finding a bad thing (Verônica).</i>

**Figure 1** - Presentation of categories and recording units that supported the thematic categorization

Before the educational activity	After the educational activity
Knowledge of the genesis of breast cancer	Knowledge of the genesis of breast cancer
<i>I do not know how it is. Now I do not remember anything. I never felt anything in the breast (Risoleta). Well, I know it is a disease that has no cure (Lia).</i>	<i>It is a disease where good cells "become crazy" and start growing very fast. It is a very serious disease that has no cure and, if not treated early on, it kills. It appears as a lump in the breast, it does not hurt. The breast becomes bulged or retracted and the skin covering the breast becomes like orange peel (Focus Group consensus).</i>
Mythical knowledge and common sense	Knowledge based on the guidelines of the National Cancer Institute
<i>My mother always told me that if a woman receives a thump in the breast, a lump comes out and turns into a cancer (Marlene). Since childhood I hear people saying that what causes this disease is when the baby burps in the breast (Carlete).</i>	<i>Being a woman is already a factor. Early menstruation, late menopause, lack of exercise, obesity, fatty food, breastfeeding for less than a year, having close relatives that had had cancer, use of drugs such as alcohol and cigarettes, not getting pregnant, getting pregnant after 30 years old, hormone replacement therapy for more than five years, and mutation of cells (Focus Group consensus).</i>
Knowledge about early detection of breast cancer	Knowledge about early detection of breast cancer
<i>I think the solution is to go to the doctor because he is the one who can find out if the woman has the disease (Gorete). I do not know what is to be learned, I just know that she (a doctor) taught me to touch the whole breast. I do not understand it (Juliana). The nurse has told me how to examine the breast and spoke of the shape of the breast, the skin appearance, but in my case, I cannot see (Aurora).</i>	<i>Ten days after menstruation, women should put a pillow on their back, if they are lying, and feel all the breast area from the outside in, in circular movements. Put arm behind the head and palpate the breast; it can be done lying down, bathing or standing. When the woman does not menstruate anymore, they should choose a day of the month and always do the self-examination on the same date. They also have to do clinical examination and mammography (Focus Group consensus).</i>

**Figure 2** - Knowledge of disabled women about breast cancer, risk factors and early detection before and after educational activities

## Discussion

A significant portion of participants are in the age group beyond that prioritized by the National Cancer Institute, which recommends screening of breast cancer for women aged 35 years and up to 69 years. Women aged 40-49 years should perform annual clinical breast examination and mammography; women aged 50-69 years, annual clinical breast examination and mammography every two years. The screening of women at high risk of breast cancer should start at age 35, with annual clinical breast examination and mammography<sup>(1)</sup>.

Schooling exerted negative influence on the answers of the 21 (29.0%) interviewed, who had laconic speech. However, despite that fact and the low level of education, participants had partial knowledge about the risk factors and the importance of early detection. These results are similar to those of a study conducted in Teresina-PI, in which women who attended elementary school (up to five years) or more

demonstrated knowledge two times higher than those illiterate or those who have studied for less than five years. Women who attended secondary school (over five years) practiced self-examination 60.0% more than those who attended elementary school<sup>(8)</sup>.

Despite the marital status not being a risk factor for breast cancer, it is worth mentioning that 33 (46.0%) participants are not single, a result close to that study done in Paraiba, Brazil, with 16 blind women, among which 6 (38.0%) reported having a partner<sup>(9)</sup>. These results contribute to demystify the social imagination that people with disabilities are asexual and cannot have children.

The origin of the knowledge of participants about breast cancer differs from that of the study in Dourados in which learning on the subject resulted from the action of professionals in the Family Basic Health Unit (48.0%) and from the media (21.0%), such as television and radio<sup>(10)</sup>. In the current study, 54 (75.0%) participants obtained information on the topic by the media, whereas 18 (25.0%) received information on Family Basic Health Units.

Regarding the risk factors for breast cancer, the percentage of answers were higher for age greater than 40 years, fatty foods, hormone replacement therapy, for short period of time breastfeeding, and trauma. In smaller percentages they cited: heredity, smoking and drinking. These results also approach those of study in Dourados with 368 women enrolled in the Family Basic Health Unit, which resulted in a high percentage of women with some knowledge about breast cancer. However, approximately half of participants did not know any of the risk factors for this disease<sup>(10)</sup>. And in the study conducted in Santiago de Cuba, the sample of 232 participants said that the prevalent risk factors for breast cancer were sedentarism, overweight, obesity and breastfeeding for less than four months<sup>(11)</sup>.

About the risk factors expressed by the participants, it is stated in the literature that age is one of the main risk factors for breast cancer, so that every five cases, four happen after 50 years of age<sup>(1)</sup>. Nevertheless, the association between hormone replacement therapy and postmenopausal breast cancer remains controversial. It is reported that the administration of estrogen alone or associated with progesterone increases the percentage of breast density. And the consensus now is that hormone replacement started in perimenopause produces high benefits. Therefore, that treatment is recommended for women 50-59 years old or with less than 10 years of menopause, when the benefits, in most cases, overcome the risks<sup>(12)</sup>.

In turn, the risk factor related to breastfeeding for less than one year was reported in a retrospective study of 504 women aged 19 to 91 years old, all diagnosed and treated for breast cancer. Results show that prolonged periods of breastfeeding suggest reducing the risk and incidence of breast cancer, even among women with family or personal history of risk for cancer<sup>(13)</sup>.

The risk factor trauma is not among those cited by the National Cancer Institute as a predictor of breast cancer. To this date, this information can be treated as a myth, an idea of common sense. And

in the case of the relationship between hereditary and breast cancer, this factor is estimated in 5-10% of cases. Family history increases two to three times the risk of this neoplasia, mainly due to mutations in the BRCA1 and BRCA2 genes, that produce proteins regulating the cell proliferation mechanism and are known as tumor suppressors. These mutations often occur at the rate of one for every 1,000 women, however, when they occur, there is risk of 50.0% of cases develop before the age of 50<sup>(14)</sup>.

The carcinogenic action of smoking has been confirmed in prospective cohort attended by 79,990 women aged 50 to 79 years old. Researchers found an increase of 20.0% to 50.0% in the risk of breast cancer in association with factors such as high intensity, long duration of smoking and age of starting smoking<sup>(15)</sup>.

Regarding the risk factor alcoholism, 59 (82.0%) participants were unaware of it. The National Cancer Institute reports that alcohol is implicated in the genesis of cancers of the oral cavity, esophagus, liver, rectum, and possibly breast, accounting for 2 to 4.0% of cancer deaths, regardless of the type of drink consumed. Based on this evidence, that institution recommends that men consume less than two drinks a day and women less than one. Adolescents and pregnant women should not consume alcohol<sup>(16)</sup>.

Participants did not mention: early menarche, late first pregnancy, nulliparity, menopause at age 50 or older and sedentary lifestyle, all of them cited by the National Cancer Institute as risk factors for breast cancer.

In this research, some participants were reluctant to participate in educational activities about breast cancer and its early detection. Some resisted out of fear; others because they did not feel vulnerable to this disease. Inference about this phenomenon is that the self-referred fear reflected the fear of disease and caused the escape from prevention. This result confirms that study on women's knowledge about breast cancer and mammography, in which authors report that some women stated they were afraid to have mammograms because they knew it was very

painful<sup>(17)</sup>.

Fear of study participants is understandable, given that breast cancer still has the connotation of mutilation, suffering and death. Added to this, it is a neoplasia with mutilating surgical indication for an organ that symbolizes femininity, sexuality and maternity. This representation of the breast is the bond that holds the will that, cornered, takes refuge and resists. These participants were asked to look for clinical examination and mammography according to the recommendations of the National Program for Breast Cancer Control.

Knowing the risk factors for breast cancer and early detection practices is essential to the successful treatment, which will enable healing. It is thanks to early detection that the most appropriate therapeutic option is established for achieving the desired results. Besides, early detection is critical to reducing the emotional harm of women, as it allows the use of more conservative and less mutilating procedures, in addition to reducing the financial burden and increased survival of the patient.

It was with this perspective that educational actions were conducted and, judging by the results, they were considered successful because the assessment of this intervention demonstrated through group consensus that most of the knowledge disseminated and discussed in focus groups was absorbed by participants.

This outcome refers to the importance of health education as a tool to value nursing and the nurse, because according to authors<sup>(18)</sup>, health education enables that the nurse, in partnership with the population, build relationship and commitment, seeking to bring benefits with improvements in living and health conditions through the involvement based in co-responsibility, able to break away from traditional, hegemonic and non-resolving health practices, towards a participatory and humane care model.

In the specific case of health education of blind people, it must be mentioned that not all nurses have

developed, in their training, skills to ensure effective communication in the context of education for blind patient's health<sup>(19)</sup>. However, this social segment needs that effective strategies are implemented to encourage the correct use of self-examination, identification of risk factors and bring awareness of the importance of the clinical breast examination and mammography as prerequisites for early diagnosis and treatment of cancer<sup>(20)</sup>.

Thus, it is up to managers to implement strategies that enable health professionals to meet the peculiarities related to these people, throughout health education. Among the skills necessary for effective interaction between blind person and nurse, it is necessary: use of spatial orientation techniques and blind person's mobility, use of information and communication technologies, such as educational materials in Braille and virtual learning environment.

## Conclusion

The percentages found regarding the age of the participants showed considerable dispersion in relation to age limits recommended by the National Cancer Institute for control and early detection of breast cancer.

In addition to the limited knowledge about breast cancer and carelessness of some women in performing the clinical breast exam, it is worth mentioning the resistance of some participants regarding the early detection of breast cancer.

Through educational activities, it was obtained increase in the degree of information of participants on breast cancer with qualitative improvement of perceived knowledge about the disease, its risk factors and early detection practices. Participants also demonstrated confidence in performing breast self-examination.

It must be stated that the results of this study are not conclusive. Its limits relate to the type of descriptive study, the qualitative approach and the use of breast self-examination, given that the National



Cancer Institute recommends the use of palpation, saying it is more efficient.

Some memory biases have occurred because various instruments have unanswered questions, since participants did not remember certain details that were important to the study and also because, in the literature, there were no publications on the same theme and involving women with visual impairment. Finally, it is suggested to carry out further studies on this theme using the self-examination technique, and that nurses implement educational activities to guide blind people about breast self-examination, frequency of gynecological visits, and the importance of periodically carrying out clinical examination and mammography.

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## Collaborations

Franca ISX, Souza FS, Silva AFR, Aragon JS, Oliveira CF and Baptista RS contributed to the analysis and interpretation of data, critical review of the relevant intellectual content and final approval of the version presented.

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