

Urinary incontinence in women: reasons for not seeking treatment

URINARY INCONTINENCE IN WOMEN: REASONS FOR NOT SEEKING TREATMENT

INCONTINENCIA URINARIA EN MUJERES: RAZONES PARA NO BUSCAR TRATAMIENTO

Lígia da Silva¹, Maria Helena Baena de Moraes Lopes²

ABSTRACT

The main purpose of this study was to verify why incontinent women, users of a Basic Healthcare Unit in Campinas, SP, do not seek treatment for urinary incontinence (UI). This is a descriptive, cross-section study, where 213 women who attended the service to have their cancer cytology examination were approached, and 35 of them, being incontinent, were included in the study. Three questionnaires were used: ICIQ-SF, King's Health Questionnaire and a specific instrument elaborated for this study. A large share of the subjects (45.7%) did not know any form of UI treatment, and more than half (65.7%) did not seek treatment for the problem, with the main stated reasons being that they thought that urinary loss was normal, did not consider it important and the physician said that it was not necessary. It is concluded that the lack of knowledge about the types of treatment can contribute for not seeking professional help.

KEY WORDS

Urinary incontinence.
Quality of life.
Women's health.

RESUMO

O objetivo principal foi verificar as razões da não procura pelo tratamento da incontinência urinária (IU) entre mulheres incontinentes, usuárias de uma Unidade Básica de Saúde em Campinas, SP. Trata-se de um estudo descritivo e transversal, no qual foram abordadas 213 mulheres que compareceram ao serviço para realizar o exame de citologia oncológica, sendo incluídas apenas 35 que eram incontinentes. Utilizaram-se três questionários: o ICIQ-SF, o King's Health Questionnaire e um instrumento elaborado para esse estudo. Grande parte dos sujeitos (45,7%) não conhecia nenhuma forma de tratamento para a IU e mais da metade (65,7%) não buscou tratamento para o problema, sendo as principais razões apontadas o fato de achar normal a perda de urina, não considerá-la algo importante e a questão do médico dizer que não era necessário. Conclui-se que o desconhecimento sobre os tipos de tratamento pode contribuir para não procurarem ajuda profissional.

DESCRIPTORIOS

Incontinência urinária.
Qualidade de vida.
Saúde da mulher.

RESUMEN

El objetivo principal fue verificar las razones de no buscar tratamiento para la incontinencia urinaria (IU) entre mujeres incontinentes, usuarias de una Unidad Básica de Salud en Campinas, SP. Se trata de un estudio descriptivo y transversal, en el cual fueron abordadas 213 mujeres que comparecieron al servicio para realizar el examen de citología oncológica, siendo incluidas apenas 35 que eran incontinentes. Se utilizaron tres cuestionarios: el ICIQ-SF, el King's Health Questionnaire y un instrumento elaborado para este estudio. Gran parte de los sujetos (45,7%) no conocía ninguna forma de tratamiento para la IU y más de la mitad (65,7%) no buscó tratamiento para el problema; siendo las principales razones apuntadas, el hecho de encontrar normal la pérdida de orina, no considerarla algo importante y la afirmación del médico de que no era necesario. Se concluye que el desconocimiento sobre los tipos de tratamiento puede contribuir para no buscar ayuda profesional.

DESCRIPTORIOS

Incontinencia urinaria.
Calidad de vida.
Salud de las mujeres.

1 Nurse. Porto Feliz, SP, Brazil. ligiadasilva_pfz@yahoo.com.br 2 Nurse. Free Lecturer. Associate Professor of the Nursing Department at the College of Medical Sciences at the State University of Campinas. Campinas, SP, Brazil. mhbaena@fcm.unicamp.br

INTRODUCTION

Urinary incontinence (UI) is currently defined by the *International Continence Society (ICS)* as *complaints about any involuntary loss of urine*⁽¹⁾, thus considering the patient's complaint, since the previous definition required the clinical observation of the problem. Indeed, research has shown that UI affects the quality of life and the social and hygienic problems have been addressed in several studies. As it is more frequent in women, several studies focus on the restrictions affecting the life of women⁽²⁾.

UI can be classified as effort incontinence (when the loss of urine occurs after physical effort, coughing or sneezing), urge-incontinence (the woman feels a sudden, hard-to-control urge to urinate) and mixed (when there are signs and symptoms of both aforementioned types)⁽³⁾. Several forms of UI treatment have been used, such as surgeries, kinesiotherapy, drug therapy, electrostimulation, among others; most of them are highly likely to be used within the primary care system.

Epidemiological studies describe an average UI prevalence of 27.6% in women and 10.5% in men⁽⁴⁾. Other studies reveal the prevalence and frequency of UI among women aged 40 to 60 years, respectively corresponding to: a few times in the year: 25% and 23%; a few times a month: 8% and 10%; few times a week: 6% and 11%; and daily, 3% and 8%⁽⁵⁾.

In addition to the physical problems, research shows that urinary incontinence affects the women's self-esteem, as well as their social activities and their ability to maintain an independent lifestyle⁽⁶⁾. Several studies reviewing the effects of UI on quality of life showed that the patients suffer social consequences, negative feelings and/or shame in 8% to 74% of the cases, with moderate to severe impact on their quality of life, 10% to 22% of times. Furthermore, another study points to changes in sexual activities in 40.9% of the cases, in addition to social (33.5%), domestic (18.9%) and occupational restrictions (15.2%)⁽²⁾.

In spite of the impact on their quality of life, relatively few incontinent women seek treatment for their problem, with rates of 6%, 11% and 14%^(3,5,7). Other studies show that 56% of incontinent women do not seek professional help; in 71% of the cases, this happens because they consider the problem to be something normal, and in 9.7% of the cases because they believe that it has no possible solution⁽⁸⁾. Some authors put forward common reasons that make a woman not seek treatment: not seeing UI as something serious or abnormal, and considering it a part of the aging process; low expectancies about treatment benefits and lack of knowledge about where to seek it; shame, hesitation or fear of seeing healthcare professionals; high costs of the medical appointments and others.

In view of this situation, where urinary incontinence is presented as a problem with relevant prevalence, interfering in the quality of life of women and with forms of treatment that can be used within the primary care system, the questions that guided our study were: do women with UI who received care in the basic healthcare units (UBS) of our city seek medical care? Do they know the available forms of service? What is the impact of UI on their daily activities? Which are the most frequent types of UI? Once the profile of urinary loss and the reasons that led these women not to seek professional help are designed, with the consequent diagnosis and resolution of this problem, adequate healthcare strategies could be developed to help these women.

Therefore, the objectives of the present study are: to identify the reasons for not seeking urinary incontinence treatment among incontinent women, users of a basic healthcare unit in the city of Campinas, SP; characterize the frequency and quantity of urinary losses, as well as the types of urinary loss (effort, urge-incontinence and mixed) according to the complaints presented by the incontinent women; identifying the restrictions they have to face due to UI; assessing their quality of life and, finally, investigating their knowledge about the forms of treatment that exist for this problem.

METHOD

This is a descriptive, cross-sectional study, performed at *Centro de Saúde Barão Geraldo*, in the city of Campinas, SP. The study included women who sought this service provider to have an oncotic cytology exam, and who reported involuntary loss of urine.

The initially established sample size was based on a previous study by one of the authors⁽⁹⁾, and consisted of 289 women, considering p (the ratio of individuals with the selected characteristic in the population) as 0.25; d (desirable difference between sample ratio and population ratio) as 0.05 and α (level of bilateral significance) as 0.05⁽¹⁰⁾. After four months of collection (in November), based on the observed prevalence, the sample size was recalculated, reaching a new total of 213 women, considering $p = 0.166$, $d = 0.05$ and $\alpha = 0.05$ ⁽¹⁰⁾.

Data collection occurred during six and a half months (early July 2005 to mid-January 2006), applying three instruments: the *International Consultation on Incontinence Questionnaire-Short Form (ICIQ-SF)*, *King's Health Questionnaire (KHQ)* and a questionnaire that was specifically elaborated for this study.

The participants were approached in the waiting room and first clarified about the research by reading the term

Epidemiological studies describe an average UI prevalence of 27.6% in women and 10.5% in men.

of consent. The three instruments were distributed in the following sequence: first, the questionnaire elaborated for this study, followed by ICIQ-SF and, finally, KHQ. Those who had never had involuntary urine loss only filled out the *age* field and returned blank questionnaires, since those who complained about this problem and accepted to take part in the study signed the term of consent and answered the questions.

The questionnaire developed by the researchers was structured in five questions, investigating age (to confirm their birth date, informed in the ICIQ-SF), the presence of urinary loss and the situations of occurrence (to characterize the type of UI), knowledge of some form of UI treatment and, finally, whether they sought treatment for the problem under study. The ICIQ-SF is a questionnaire with six questions that contemplate birth date (1), gender (2), frequency of urinary loss (3), amount of urine the individual thinks that is lost (4), the interference of this loss in daily life (5) and when it occurs (6). A partial score was attributed to each answer of questions 3, 4, and 5. The total score was obtained from the added results of these three questions; the higher the value, the higher the impact on the quality of life, with a maximum value of 21. The version of the KHQ validated for the Portuguese language evaluates nine dimensions of quality of life: general perception of health, impact of the incontinence, limitations in daily activities, physical limitations, social limitations, personal relationships, emotions, sleep and energy and measures of gravity, in addition to a list of symptoms that could be associated to urinary loss. Scores vary from zero to 100 in each dimension, with a value of 100 indicating the worst quality of life. Both ICIQ-SF and KHQ were validated for the Portuguese language⁽¹¹⁻¹²⁾.

The continuous variables (age, ICIQ-SF and KHQ scores) were analyzed descriptively (average, standard deviation, median, minimum and maximum values), and the frequencies of the categorical variables (questionnaire topics) were calculated. Also, the ICIQ-SF and KHQ scores were calculated.

The Ethics Committee of Faculdade de Ciências Médicas da UNICAMP approved the research in June 2005 (file #281/2005).

RESULTS

Over six and a half months of data collection, 213 women were approached, 35 (16.4%) of whom reported involuntary loss of urine and were included in the present study. Average age was 44.3 years, varying from 21 to 76 years old.

A large share of the participants knew no form of treatment for the condition and, among those who did, it was

observed that surgical therapy was prevalent over the others, as shown in Table 1.

Table 1 - Distribution of the women who received care in a basic healthcare unit according to the types of urinary incontinence treatment that they knew - Campinas, SP - July 2005 to January 2006.

Type of treatment	N	%
None	16	45.7
Surgery	13	37.1
Medication	2	5.7
Others (tea)	1	2.9
Exercise	1	2.9
Exercise /Medication	1	2.9
Surgery /Exercise/Physical Therapy	1	2.9
Total	35	100

We found that more than half of the women did not seek treatment for UI. Among those who did, surgical therapy was predominant (Table 2).

Table 2 - Distribution of the women who received care in a basic healthcare unit according to the types of urinary incontinence treatment that they sought - Campinas, SP - July 2005 to January 2006.

Type of treatment	N	%
None	23	65.7
Surgery	6	17.1
Medication	2	5.7
Others (tea)	1	2.9
Exercise	1	2.9
Exercise /Medication	1	2.9
Surgery /Exercise/Physical Therapy	1	2.9
Total	35	100

The women reported several reasons not to seek treatment for UI. The most frequent was the fact that they thought that urinary loss was normal. They did not consider it an important problem and mentioned the fact that the physician said that it was not necessary (Table 3).

Table 3 - Distribution of the women who received care in a basic healthcare unit according to the alleged reasons for not seeking urinary incontinence treatment - Campinas, SP - July 2005 to January 2006.

Reason	N	%
The physician said it was not necessary	4	17.4
Losing urine is normal	4	17.4
Does not have time / It is not important / Has other problems to see to	4	17.4
Urinary loss is small / It does not bother them much / It is a recent problem	3	13.0
They do not know types / options for treatment	3	13.0
awaiting test results exams	2	8.7
Is ashamed	1	4.3
Thinks that it is no use treating, there is no cure	1	4.3
Is afraid to have a surgery	1	4.3
Total	23	100

Regarding the type of UI, 51.4% (18) of the women have mixed UI; 34.3% (12) have urge-incontinence, and 14.3% (5) have effort incontinence.

According to the categories present in the ICIQ-SF, the following variables were investigated: the frequency of the urinary losses (item 3), the amount of urine the participants believe that they lose (item 4) and the interference of these losses in their daily lives (item 5), among others.

For item 3, it was observed that 20% (7) of the participants reported losses once a week or less frequently; 2.9% (1) two to three times a week; 11.4% (4) once a day; 57.1% (20) several times a day, and 8.6% (3) all the time.

When the participants were asked about the amount of urine they believed that they lost (item 4), 60% (21) believed that they lost a small amount of urine, followed by 20% (7) who believed that they lost a moderate amount and 20% (7) who mentioned losses in large amounts.

Figure 1 describes the scores, from zero to 10, the women attributed to the interference of the urinary losses in their daily lives, according to the ICIQ-SF. It should be noted that many of them consider urinary incontinence as something that interferes a lot in their daily activities, thus attributing scores of 10 in this category.

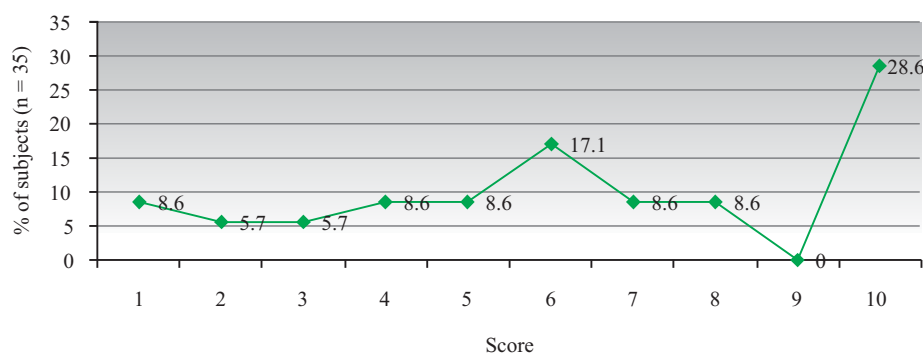


Figure 1 - Scores attributed to the interference of urinary incontinence in daily activities (0 = no interference; 10 = interferes a lot) - Campinas, SP - July 2005 to January 2006.

The average ICIQ-SF score was 12.83, varying from 4 to 21, with a standard deviation of 4.89 and median of 13.

Table 4 describes the scores obtained in the different domains of the KHQ (from 0 to 100 points). The highest

score is noted in the domain *impact of the incontinence* (average score of 66.7), while the lowest score recorded is in the *social activities* domain (14.8).

Table 4 - Distribution of the women who received care in a basic healthcare unit according to the scores obtained in the different domains of the KHQ - Campinas, SP - July 2005 to January 2006.

Domain	Average	S.D.	Minimum	Maximum	Median
Impact of the incontinence	66.7	30.3	0	100	66.7
Measures of gravity	47.2	24.0	0	100	46.7
General perception of health	44.3	28.5	0	100	25.0
Limitation of daily activities	43.8	37.3	0	100	33.3
Emotions	41.3	36.1	0	100	33.3
Sleep and energy	39.5	36.6	0	100	33.3
Physical limitations	37.6	39.9	0	100	33.3
Personal relations	21.2	34.9	0	100	0
Social limitations	14.8	27.3	0	100	0

DISCUSSION

The results about the types of UI found, with 51.4% of women with mixed UI, 34.3% with urge-incontinence and 14.3% with effort incontinence, are different from studies held in other countries. These showed that effort UI is prevalent in 50% of the cases, mixed UI in 32% and urge-incontinence in 14%, with the remaining 4% included in the category *others*⁽⁴⁾. A study about epidemiology and natural history of UI in women confirms the aforementioned findings, concluding that nearly half of all incontinent women are classified as having effort UI, with a smaller proportion having mixed incontinence and the lowest amount of them being urge-incontinent⁽¹³⁾. However, studies based on symptomatology (clinical complaints) instead of clinical or urodynamic exams have higher rates of mixed UI. In Norway, in a prospective cohort study involving 2845 women, the symptomatology based on the patients' answers showed ratings of 64%, 24% and 9% for mixed incontinence, effort incontinence and urge-incontinence, respectively⁽¹⁴⁾. In our midst, a retrospective study based on the service provided to 114 patients observed that complaints of isolated urinary losses due to efforts were mentioned by 41 patients (36.0%); isolated urge-incontinence was reported by 13 (11.4%) and mixed symptoms by 60 (52.6%)⁽¹⁵⁾.

The high proportion of subjects reporting urinary losses several times a day stands out, in quantities from moderate to large, which does not agree with the findings in literature. These point to a UI frequency with daily losses of 3% and 8% in women aged 40 and 60 years, respectively⁽⁵⁾.

Impacts on quality of life were clearly shown by 28.6% of the subjects, who attributed a score of 10 to the interference caused by urinary loss in daily life, as well as the average score of 12.8 in the ICIQ-SF and the relatively high average scores noted in the KHQ, especially in the dimen-

sions impact of incontinence (66.7), measures of gravity (47.2), perception of health (44.3%) and important limitation of daily activities (43.8). These findings, related to the impact of UI in the life of women, are consistent with those found in an article⁽⁴⁾ that assessed 14 studies that demonstrated the effects of UI in quality of life, revealing that the patients have social consequences, negative feelings and/or shame in 8% to 74% of the cases. The impact on quality of life was moderate to severe in 10% to 22% of the patients. Furthermore, UI interfered in marital and sexual life in 7.5% to 33% of the study subjects.

The same authors also mention that, although 50% of the patients report that UI affects their quality of life somewhat, 77% of them have not yet sought help for their condition. Similar figures were observed among the women of the studied UBS (65.7%), who mentioned several reasons for not seeking treatment. They thought it was normal to lose urine or they did not consider it an important or priority problem. It is worth noting that, in some cases, a physician mentioned that treatment was not necessary. The fact of thinking that urinary loss is normal and not considering it important is also shown in other studies^(4,16). However, the medical attitude (physicians saying that treatment was not necessary) points to the need for information and updating of healthcare professionals regarding UI handling, including non-surgical forms of treatment that can be used within the primary care system.

Therefore, contradictions appear between our findings and other studies of the same type, therefore, show contradictions. Although urinary incontinence is one of the most frequent aggravations to women's health, affecting their quality of life, seeking treatment is not a priority.

Many of the women in the studied group did not know any form of treatment, or knew only about the surgery,

which was the most common option among those seeking professional help – probably because it was the most well-known type of treatment. However, it is known that UI control can be surgical, pharmacological or behavioral. Exercises for the pelvic muscles, as the least invasive method, should be the first choice, either associated to other forms of treatment or not.

In order to cause changes, educational actions promoting reflection and offering clarifications about UI, its impact on quality of life, its handling and treatment are necessary for the general population and also for healthcare professionals, so that they can provide adequate care to those seeking help. However, better availability of, services and better preparation of, healthcare professionals, although necessary and indispensable, may not be able to revert this situation isolatedly, unless other strategies are also used, such as publications, debates in the media and campaigns focused on awareness of the problem.

CONCLUSIONS AND FINAL CONSIDERATIONS

The main reasons for women not to seek treatment are similar to other studies, noting the fact that physicians said that treatment was not necessary, finding it normal to lose urine and having no time or thinking that the problem was not important.

Although the amount of lost urine is small, in most cases, a significant number (40%) had losses from moderate to large, with urinary losses occurring several times a day. Most had mixed UI, partially contradicting the findings of literature.

Regarding quality of life, nearly one third attributed the maximum score to the interference in daily activities. The

domain *impact of the incontinence* was the most affected, and the domain *social limitations* the least.

Women, mostly, do not know forms of treatment, which is one of the reasons why they do not seek professional help.

Deficient or wrong knowledge may also contribute for them not to valorize or prioritize UI treatment. With aging, the prevalence of UI increases⁽¹⁷⁾, even in cases where urinary loss is small or less frequent. Exercises of the pelvic floor should be recommended so that the symptoms will not be aggravated as the patient ages.

However, in our reality, pelvic floor rehabilitation programs are not available in basic healthcare services. These programs could be implemented and led by trained nurses, as already occurs in other countries⁽³⁾. These professionals, along with the physicians and nursing assistants, are present in all UBSs and are members of the family healthcare teams. The creation of such a program could have an important impact on the health of the women, since UI is one of the most prevalent conditions and affects their quality of life considerably. In addition, the costs to treat it are high, especially in the use of diapers and other devices, causing an individual and public impact. It is not enough to develop studies identifying the problem – it is necessary to implement intervention projects and develop studies assessing its impact.

The nurses should be socially committed to revert this situation of lack of information and offering services, since they have technical and legal competence to act and specialized courses in stomal therapy and urology to acquire the necessary skills, in case they have not received this type of instruction during their undergraduate years. It is worth noting that, as we see it, rehabilitation of the pelvic floor and dealing with urinary incontinence should be a part of the undergraduate nursing course curriculum, and this step has already been taken at our university.

REFERENCES

1. Abrams P, Cardoso L, Fall M, Griffiths D, Rosier P, Ulmesten U, et al. The standardization of terminology of lower urinary tract function: report from the standardization sub-committee of the international continence society. *Urology*. 2003;61(1):37-49.
2. Lopes MHB, Higa R. Restrições causadas pela incontinência urinária à vida da mulher. *Rev Esc Enferm USP*. 2006; 40(1):34-41.
3. Simeonova Z, Milsom I, Kullendorf AM, Molander U, Bengtsson C. The prevalence of urinary incontinence and its influence on the quality of life in women from an urban Swedish population. *Acta Obstet Gynecol Scand*. 1999;78(6):546-51.
4. Minassian VA, Drutz HP, Al-Badr A. Urinary incontinence as a worldwide problem. *Int J Gynecol Obstet*. 2003;82(3):327-38.
5. Eva UF, Gun W, Preben K. Prevalence of urinary and fecal incontinence and symptoms of genital prolapse in women. *Acta Obstet Gynecol Scand*. 2003;82(3):280-6.
6. Fitzgerald S, Palmer M, Berry SJ, Hart K. Urinary incontinence: impact on working women. *AAOHN J*. 2000;48(3):112-8.
7. Hägglund D, Walker-Engström ML, Larsson G, Leppert J. Quality of life and seeking help in women with urinary incontinence. *Acta Obstet Gynecol Scand*. 2001;80(11):1051-5.
8. Modroño Freire MJ, Sánchez Cougil MJ, Gayoso Diz P, Valero Paternain M, Blanco Ramos M, Cuña Ramos F. O. Estudio de prevalencia de incontinencia urinaria en mujeres de 18 a 65 años y su influencia en la calidad de vida. *Aten Primaria*. 2004;34(3):134-9.

9. Elias RC, Lopes MHBM. Prevalência de incontinência urinária entre mulheres atendidas em uma unidade básica de saúde no município de Campinas, SP. In: Anais do 10º Congresso Interno de Iniciação Científica da Unicamp; 2002 set. 25-26; Campinas, BR. Campinas: UNICAMP; 2002. p. 29.
10. Hulley SB, Cummings SR. Designing clinical research. Baltimore: Williams & Wilkins; 1988.
11. Tamanini JTN, D'Ancona CAL, Botega NJ, Netto Jr NR. Validação do "King's Health Questionnaire" para o português em mulheres com incontinência urinária. Rev Saúde Pública. 2003;37(2):203-11.
12. Tamanini JTN, Dambros M, D'Ancona CAL, Palma PCR, Rodrigues Netto N Jr. Validação para o português do "International Consultation on Incontinence Questionnaire – Short Form" (ICIQ-SF). Rev Saúde Pública. 2004;38(3):438-44.
13. Hunskaar S, Burgio K, Dikno A, Herzog AR, Hjalmas K, Lapitan MC. Epidemiology and natural history of urinary incontinence in women. Urology. 2003;62 Suppl 4A:16-23.
14. Indrekvam S, Fosse OAK, Hunskaar SA. Norwegian national cohort of 3198 women treated with home-managed electrical stimulation for urinary incontinence. Scand J Urol Nephrol. 2000;35(1):26-31.
15. Feldner Jr PC, Bezerra LRPS, Girão MJBC, Castro RA, Sartori MGF, Baracat EC et al. Valor da queixa clínica e exame físico no diagnóstico da incontinência urinária. Rev Bras Ginecol Obstet. 2002;24(2):87-91.
16. Guarisi T, Pinto-Neto AM, Osis MJ, Pedro AO, Costa-Paiva LHS, Faúndes A. Procura de serviço médico por mulheres com incontinência urinária. Rev Bras Ginecol Obstet. 2001; 23(7): 439-43.
17. Hannestad YS, Rortveit G, Sandvik H, Hunskaar S. A community-based epidemiological survey of female urinary incontinence: the Norwegian EPINCONT study. Epidemiology of Incontinence in the County of Nord-Trondelag. J Clin Epidemiol. 2000;53(11):1150-7.

Scientific Initiation Project funded by the PIBIC-CNPq Program.