


A Questionnaire-based Study on Patient's Awareness Regarding Cardiac Valve Prosthesis Knowledge and Risk Perception

Questionário sobre Conhecimento e Perceção de Risco em Doentes Portadores de Prótese Valvular Cardíaca

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Abstract

Introduction: In the occidental world, heart valve disease, mainly degenerative, is increasing with a higher rate of cardiac valve prosthesis implantation. Health literacy can impact health outcomes. The aim of this study was to understand in patients with cardiac valve prosthesis the patterns of knowledge regarding their own valve's pathology, related complications, and their current multidisciplinary medical surveillance.

Methods: Cross-sectional study on a group of patients with cardiac valve prosthesis, consisting of a 13-question instrument application (demographic, medical surveillance, medical background, and prosthesis related complications).

Results: Fifty two patients completed the questionnaire, 48% male, 67.2±12.3 years old. A percentage of 88% had a mechanical valve. A total of 63% reported caries and periodontal disease. A percentage 48% could not identify the reason for valve replacement and 19% could not identify the location for the prosthesis. The majority had regular cardiological surveillance. Nevertheless, annual dental surveillance was only present in 38% of the inquired patients. Finally, 70% of patients could not identify one single prosthesis related complication.

Conclusion: Further studies, involving several centres in different regions of Portugal are needed to further understand or confirm the described situation. Patient's education is fundamental to improve health literacy with an impact on health outcomes.

Keywords: Awareness; Health Knowledge, Attitudes, Practice; Heart Valve Prosthesis; Surveys and Questionnaires

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Data confidentiality: In all patients a written informed consent was obtained.

Resumo

Introdução: No mundo ocidental, a doença valvular cardíaca, principalmente degenerativa, tem aumentado o que tem levado a um aumento da taxa de implantação de próteses valvulares cardíacas. A literacia em saúde pode ter impacto nos resultados da saúde. O objetivo deste estudo foi compreender em doentes com prótese valvular cardíaca os padrões de conhecimento relativos à patologia da sua própria válvula, complicações relacionadas e a vigilância multidisciplinar médica atual.

Métodos: Estudo transversal sobre um grupo de doentes portadores de prótese valvular cardíaca, através da utilização de um questionário com 13 itens (demografia, vigilância médica, história médica pregressa e complicações relacionadas com a prótese).

Resultados: Cinquenta e dois doentes preencheram o questionário, 48% masculino, 67,2±12,3 anos. Dos doentes, 88% tinham uma válvula mecânica. A maioria tinha vigilância cardiologia regular. No entanto, a vigilância dentária anual só se verificou em 38% dos doentes inquiridos. Finalmente, 70% dos pacientes não conseguiram identificar uma única complicação relacionada com a prótese.

Conclusão: São necessários mais estudos, envolvendo várias instituições de saúde, em diferentes regiões de Portugal, para compreender ou confirmar melhor a situação descrita. A educação do paciente é fundamental para melhorar a literacia em saúde com impacto nos resultados da saúde.

Palavras-chave: Conhecimento; Conhecimentos, Atitudes e Prática em Saúde; Inquéritos e Questionários; Próteses Valvulares Cardíacas

Introduction

In industrialized countries such as the USA, valvular heart disease has a prevalence of 2.5% in the general population, increasing its prevalence in older patients as a result of a predominant degenerative etiology.¹ Rheumatic aetiology used to be the most frequent aetiology but has been largely supplanted by degenerative aetiology in the last decades.² Cardiac valve interventions with prosthesis implantations has been increasing,^{3,4} growing the total number of patients with prosthetic valves in our daily practice. Nevertheless, prosthetic valve implantation has risks and benefits for the patient⁵ and informed patient preference is currently fundamental in the decision on the type of valve implanted and on the impact on the eventual complications afterwards.

According to World Health Organization (WHO), health literacy can impact health outcomes in several ways. A fragile health literacy result in less healthy choices, riskier behaviour, poorer health, less self-management and more hospitalization.⁶

In Portugal, a gradual aggravation of the population aging⁷ with a sustained increase in the aging index of the population⁸ has been shown and the rate of illiteracy in the census of 2011 was 5.2%. Also, a recent survey on health literacy in Portugal showed that older people presented a higher proportion of more limited levels of literacy, also related to a lower level of education.⁹

The aims of this study were to present data on the knowledge, medical surveillance, and complications awareness regarding valve pathology in a sample of carriers of prosthetic cardiac valves, in a region of Portugal.

Methods

The procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and

to the Helsinki Declaration of the World Medical Association updated in 2013.

This study was authorized by the Local Ethics Committee on the 14th July 2016 (protocol number 29).

Study design

This was a cross sectional descriptive study and was carried out from 1st June to 31st August 2017 at the Anticoagulation Outpatient Clinics at Centro Hospitalar Barreiro Montijo, in Portugal. This hospital centre covers a geographical area with an estimated population of about 233 000 inhabitants, according to the last national census of 2011.

A questionnaire with 13 questions – see Supplement Table S1 – was applied to a sample of patients with cardiac valve prosthesis.

Sample

The questionnaire was applied to a group of patients that were admitted in the Anticoagulation Outpatient Clinics for INR control during the study period and that accepted to participate.

Inclusion criteria: ≥ 18 years old; with a cardiac valve prosthesis; capacity to cooperate and understand the questionnaire.

Exclusion criteria: < 18 years old; unwilling to cooperate; incapacity to understand and answer the questions.

Illiterate patients that complied with all inclusion criteria and had no exclusion criteria also participated with the aid of an unbiased person to the study from the staff of the Anticoagulation Outpatient Clinics.

Collection of data

The questionnaire was applied to all patients after the consul-

tation. An oral information on the aim and content of the questionnaire was provided by the responsible nurse. In all patients a written informed consent was obtained.

The questionnaire had 13 questions with multiple choice or short answer questions. Four main domains were analysed such as demographic characterisation (question 1), medical background (questions 2 to 4), current medical surveillance (questions 5 to 7) and valve related complications perception (remaining questions).

Statistical analysis

A descriptive analysis of the results was performed.

Continuous variables were presented as mean ± standard deviation and categorical variables expressed as frequencies and percentages.

The data was analyzed using Excel 365 for Windows software.

Results

A total of 52 questionnaires were completely assembled. The patients had an average age 67 years old (minimum 21 and maximum 84 years old), with 25 (48%) were male (Table 1).

Table 1. Demographic characteristics of the patient’s sample that participated in the survey.

	Overall n=52
Male gender, n (%)	25 (48)
Age, average years old	67.2 ±12.3
Group age, years old, n (%)	
21-40	1 (2)
41-60	12 (23)
61-80	34 (65)
≥ 81	5 (10)
School level, n (%)	
None	1 (2)
First cycle	34 (65)
Lower secondary	7 (13)
Higher secondary	6 (12)
University	3 (6)

Medical background

Regarding medical background, a significant prevalence of cardiovascular pathology is present including heart failure, arrhythmias, and ischemic coronary and cerebrovascular disease. Caries and periodontal disease affect more than half the sample (63.5%) (Fig. 1A).

Forty six patients (88%) had a mechanical prosthetic valve.

Clinical diagnosis accountable for valve replacement was unknown in 48% of responders. The remaining identified chronic regurgitation and stenosis as the main reason for surgical intervention. Valve lesion derived from an acute myocardial infar-

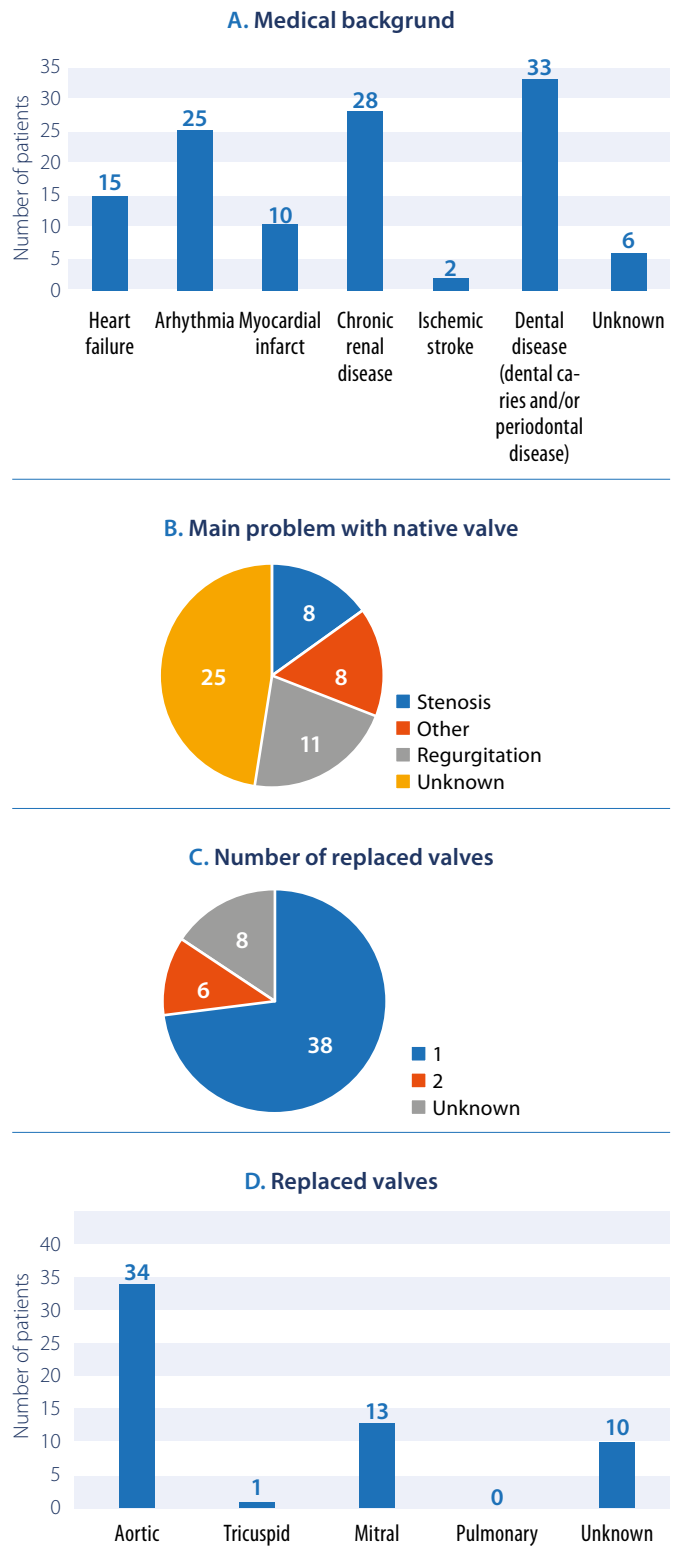


Figure 1. A. current medical pathologies; B. principal problem related to the replaced native valve; C. number of native valves intervened and replaces; D. replaced valves in the patients that completed the questionnaire.

tion complication was identified in one responder, infective endocarditis was the cause in three patients and aortic aneurism related valve lesion was appointed by one patient (Fig. 1B).

The majority reported that only one valve was replaced, the aortic location was the most prevalent cardiac valve prosthesis.

Fifteen percent of the total cohort did not know the number of replaced valves and 19% could not name which valve had been replaced (Figs. 1C and 1D).

Medical surveillance

Most patients have a regular follow-up in a cardiology consultation (Table 2). Nearly 85% perform blood analysis once a year and 73.1% have performed an echocardiogram in the last 2 years.

Table 2. Cardiac valve medical supervision.

	n	%
Cardiac valve clinics		
1/year	31	59.6%
Every 2 years	2	3.8%
> 1/year	12	23.1%
Every 3 years	0	0.0%
> 3 years	0	0.0%
Does not know	3	5.8%
Not regularly followed	4	7.7%
Blood analysis		
> 1/year	23	44.2%
1/year	21	40.4%
Every 2 years	2	3.8%
Other	1	1.9%
Unknown	5	9.6%
Years since last echocardiography performed		
10 years	1	1.9%
3 Years	3	5.8%
2 years	8	15.4%
1 year	18	34.6%
Current year	12	23.1%
Unknown	10	19.2%

Regarding dental care after cardiac valve surgery, 24 patients (46.1%) report attending dentist at least every two years. Nevertheless, 20 (28.4%) report not attending any consultation and of those, 7 report having a complete dental prosthesis (Fig. 2).

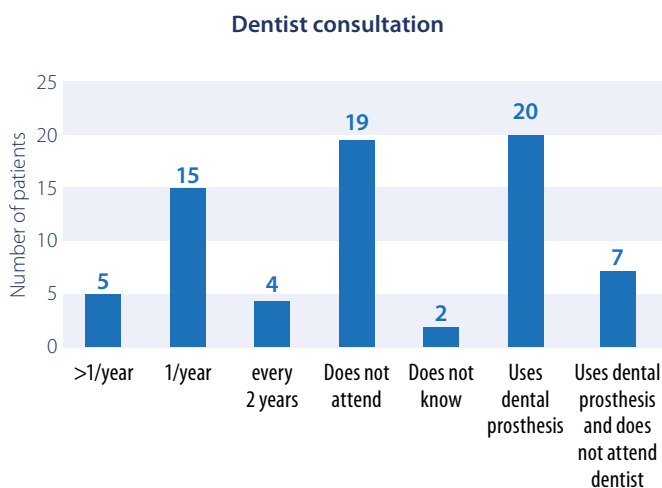


Figure 2. Dental management in patients with cardiac valve prosthesis.

Valve prosthesis complications awareness

Concerning the complications that can arise in patients with cardiac valve prosthesis, this cohort in its majority was unaware of them (Table 3). In fact, nearly 70% of patients was unable to identify complications related to cardiac valve prosthesis.

Table 3. Cardiac valve prosthesis’s complications perception.

	Mechanical prosthesis n=46	Biological prosthesis n=6
Infection	11	0
Bleeding	13	0
Thrombus	11	0
Degeneration	NA	0
Anemia	2	0
Other	0	0
Unknown	30	5
Missing	0	1

NA: not applicable.

Finally, only 10 patients were aware that cardiac valve surgery reoperation was a possibility.

Discussion

This a unique study analysing the knowledge and complication awareness regarding valve pathology in carriers of prosthetic cardiac valves in Portugal. The main findings in this small sample were: 1) the majority had a regular follow-up in a speciality consultation; 2) a significant proportion was unaware of the reason to have had a prosthesis implantation or its location; 3) nearly 65% reported the presence of dental disease but a significant proportion did not attend regular dental consultation; and finally, 4) more than two thirds acknowledged that they could not name prosthesis related complications.

So far, definitive treatment in severe heart valve disease still relies on surgical repair or replacement,¹⁰ with a positive impact in life expectancy. This has led to an increasing prevalence of patients with prosthetic heart valve worldwide.¹¹ In fact, progressive improvement in complex valve surgery and the advent of percutaneous valve implantation, especially in the treatment of severe aortic valve stenosis have contributed to this increasing prevalence, even in the elderly or high-risk patients.

However, heart valve prosthesis carries a significant risk of complications derived from a higher risk of thrombosis, infection, degeneration, or dehiscence. A multidisciplinary approach including a heart valve specialist, a cardiac surgeon, an interventional cardiologist, an imaging subspecialist, a dedicated nurse and other specialities such as pneumology should be integrated in a “heart valve team”¹² and responsible for the regular follow-up of heart valve patients. On the other hand, patients’

active involvement is crucial to improve his quality of life after heart valve surgery as well as allows for the early identification of clinical symptoms related to complications.¹² Patient's education and awareness regarding heart valve prosthesis surveillance are cornerstone features in a successful heart valve clinics.

This group of heart valve prosthesis carriers was predominantly older and with a low level of education. As mentioned previously this is in accordance with the general Portuguese demographic trends. Also, in 2017 the rate of people over 15 years old in Portugal with no school level or with a complete first cycle was respectively 7.3% and 22.4%, revealing that education attainment level in the general population in Portugal is still quite low, compared with the majority of other countries of the EU,¹³ particularly in the older group ages (55 years old and older).

No information regarding their social situation was collected. Still, the purchasing power in this region of Portugal is equivalent to the national average in most of its counties.¹⁴

Therefore, the low to moderate level of knowledge concerning valve pathology and related complications may partly be explained by the predominant age group and level of education that can directly affect health literacy in this group of patients.

Rocha *et al*¹⁵ performed a survey on patients with mechanical cardiac valves and their knowledge concerning chronic oral anticoagulation therapy and concluded that it was moderate with a significant percentage could not name one single factor that could alter INR or report their INR target range. One other study¹⁶ that analysed the factors that predicted a better understanding of anticoagulation treatment were younger age and improved information on anticoagulation.

Dental care in this group of patients was inadequate, with a high proportion acknowledging caries and periodontal disease as well as partial/complete dental prosthesis. Also, dental surveillance was absent in a significant part of the sample. In fact, poor oral hygiene has been recognized as a risk factor for endocarditis and bacteriemia^{17,18} with a direct impact in cardiac valve prosthesis carriers. Dental hygiene and antibiotic prophylaxis during gingival and periapical region of the teeth or oral mucosa manipulation are indicated by scientific guidelines.¹⁹

Limitations

Limitations to the current study were: 1) the information provided by the patients regarding their medical background, type of valves, location and reasons to valve replacement were not confirmed by consulting the patients hospital records which could have identified a bigger proportion of incorrect information; 2) the fact that the patients filled in the questionnaire themselves and were predominantly older could have led to misinterpretation of some questions influencing the final answer; 3) the questionnaire used has not been validated.

Conclusion

The fact that the survey was undertaken in a small sample of carriers of cardiac valve prosthesis from a non-central hospital does not allow for general considerations. Nevertheless, it is notable that low to moderate knowledge regarding own's pathology and prosthesis related complications in this group of patients was noted as well as an alarming lack of dental surveillance in a significant part of the sample.

We consider that performing high quality multicentre case-control studies, and from different regions of Portugal could contribute to a better understanding of this situation. Still, education based on a multidisciplinary approach at the time of hospitalization, discharge and during follow-up consultations could improve health literacy, with a positive impact on the level of health, less hospitalizations, and events.

PREVIOUS PRESENTATIONS

This work was submitted and presented at a National Cardiology Meeting, Sul e Ilhas 2018, as a poster with discussion.

Responsabilidades Éticas

Conflitos de Interesse: Os autores declaram a inexistência de conflitos de interesse na realização do presente trabalho.

Fontes de Financiamento: Não existiram fontes externas de financiamento para a realização deste artigo.

Confidencialidade dos Dados: Os autores declaram ter seguido os protocolos da sua instituição acerca da publicação dos dados de doentes.

Proteção de Pessoas e Animais: Os autores declaram que os procedimentos seguidos estavam de acordo com os regulamentos estabelecidos pelos responsáveis da Comissão de Investigação Clínica e Ética e de acordo com a Declaração de Helsínquia de 2013 da Associação Médica Mundial.

Proveniência e Revisão por Pares: Não comissionado; revisão externa por pares.

Ethical Disclosures

Conflicts of interest: The authors have no conflicts of interest to declare.

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Confidentiality of Data: The authors declare that they have followed the protocols of their work center on the publication of data from patients.

Protection of Human and Animal Subjects: The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics

Committee and to the 2013 Helsinki Declaration of the World Medical Association.

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Supplement

Versão Portuguesa

PARTE I

Inquérito sobre Próteses Valvulares

1. Qual a sua idade: _____ anos Sexo: _____ Ano de escolaridade? _____

2. Tem/Teve alguma doença conhecida – pode escolher mais do que uma opção?

- | | |
|---|---|
| O coração não bombeia bem/coração fraco (insuficiência cardíaca) <input type="checkbox"/> | Arritmia <input type="checkbox"/> |
| Ataque do coração (enfarte do miocárdio) <input type="checkbox"/> | Dentes estragados (cáries) <input type="checkbox"/> |
| Os rins não funcionam bem (doença renal crónica) <input type="checkbox"/> | AVC (trombose cerebral) <input type="checkbox"/> |
| Problemas nas gengivas (doença periodontal) <input type="checkbox"/> | Não sei <input type="checkbox"/> |

3. Sabe a razão pela qual teve de substituir a válvula do coração?

- | | |
|--|----------------------------------|
| A válvula não abria bem (estenose) <input type="checkbox"/> | Outro motivo. Qual? _____ |
| A válvula tinha fugas (insuficiência) <input type="checkbox"/> | Não sei <input type="checkbox"/> |

Indique o número de válvulas cardíacas que teve de substituir: _____ Não sei

4. Sabe qual/ quais a(s) válvula(s) que substituiu?Válvula aórtica Válvula mitral Não sei Válvula tricúspide Válvula pulmonar **5. De quanto em quanto tempo tem consulta de cardiologia?**Geralmente tenho 1 consulta por ano Geralmente tenho mais de 1 consulta por ano Mais de 3 anos Não sou seguido(a) em Cardiologia 2 em 2 anos 3 em 3 anos Não sei **6. De quanto em quanto tempo costuma fazer análises (as avaliações de INR não contam)?**Mais de 1 vez por ano Só faço de 2 em 2 anos Não sei Só faço 1 vez por ano

Outra frequência. Qual? _____

7. Com que frequência costuma ir ao dentista?Mais de 1 vez por ano De 2 em 2 anos Não vou ao dentista Tenho placa dentária 1 vez por ano

Outra frequência. Qual? _____

Não sei **8. Em que ano fez o último ecocardiograma? _____****PARTE II****(Se tem Prótese Valvular Mecânica responda a estas perguntas)****9. Sabe quais são os riscos associados à prótese mecânica?**Infecção Coágulo/trombo Não sei Hemorragia Anemia

Outro risco. Qual? _____

PARTE III**(Se tem Prótese Valvular Biológica responda a estas perguntas)****10. Sabe quais os riscos associados à prótese biológica?**Prótese estragar-se com o tempo (degeneração) Necessidade de ser novamente operado Não sei Infecção Coágulo/trombo

Outra complicação. Qual? _____

PARTE IV**11. Alguma vez alguém o/a informou sobre a possibilidade de ser novamente operado?**Sim Não **12. Alguma vez teve de ser novamente operado/(a) por problemas com a prótese?**Sim Não

Se respondeu "SIM" à questão 13, por favor responda às 3 últimas perguntas:

Quantas vezes foi novamente operado por problemas na prótese? _____

Qual o ano em que voltou a ser novamente operado? _____

Indique o motivo pelo qual teve de ser novamente operado: _____

English version

PART I
Survey on valve prostheses

1. Your age: _____ years Gender: _____ Degree of education? _____

2. Do/Did you have any known diseases? – You can choose more than one option.

- | | |
|--|---|
| The heart does not pump well/weak heart (heart failure) <input type="checkbox"/> | Arrhythmia <input type="checkbox"/> |
| Heart attack (myocardial infarction) <input type="checkbox"/> | Damaged teeth (caries) <input type="checkbox"/> |
| Kidneys do not work well (chronic kidney dysfunction) <input type="checkbox"/> | Stroke (cerebral thrombosis) <input type="checkbox"/> |
| Gum problems (periodontal disease) <input type="checkbox"/> | I do not know <input type="checkbox"/> |

3. Do you know the reason you had to replace the heart valve?

- | | |
|--|--|
| The valve does not open well (stenosis) <input type="checkbox"/> | Other reason. Which? _____ |
| The valve have leaks (insufficiency) <input type="checkbox"/> | I do not know <input type="checkbox"/> |

4. Indicate the number of heart valves you had to replace: _____ I do not know

5. Do you know which valve(s) you replaced?

- | | |
|--|--|
| Aortic valve <input type="checkbox"/> | Tricuspid valve <input type="checkbox"/> |
| Mitral valve <input type="checkbox"/> | Pulmonar valve <input type="checkbox"/> |
| I do not know <input type="checkbox"/> | |

6. How long do you have a cardiology consultation?

- | | |
|--|--|
| I usually have 1 appointment per year <input type="checkbox"/> | 2 in 2 years <input type="checkbox"/> |
| I usually have more than 1 appointment per year <input type="checkbox"/> | 3 in 3 years <input type="checkbox"/> |
| More than 3 years <input type="checkbox"/> | I do not know <input type="checkbox"/> |
| I am not followed in Cardiology appointment <input type="checkbox"/> | |

7. How much time do you do analysis (INR assessments does not count)?

- | | |
|--|---|
| More than 1 time per year <input type="checkbox"/> | I only do it once a year <input type="checkbox"/> |
| I only do it two in two years <input type="checkbox"/> | Another frequency? _____ |
| I do not know <input type="checkbox"/> | |

8. How often do you go to the dentist?

- | | |
|---|--|
| More than once a year <input type="checkbox"/> | Once a year <input type="checkbox"/> |
| 2 in 2 years <input type="checkbox"/> | Another frequency? _____ |
| I do not go to the dentist <input type="checkbox"/> | I do not know <input type="checkbox"/> |
| I have dental plaque <input type="checkbox"/> | |

9. When did you do your last echocardiogram? _____

PART II

(If you have a Mechanical Prosthesis answer these questions)

10. Do you know the risks associated to mechanical prosthesis?

- | | |
|--|-----------------------------------|
| Infection <input type="checkbox"/> | Bleeding <input type="checkbox"/> |
| Clot/thrombus <input type="checkbox"/> | Anemia <input type="checkbox"/> |
| I do not know <input type="checkbox"/> | Another risk? _____ |

PART III

(If you have a Biological Prosthesis answer these questions)**11. Do you know the risks associated to biological prosthesis?**Prosthesis spoil with time (degeneration) Infection Submitted to surgery again Clot/thrombus I do not know

Another complication? _____

PART IV

12. Has anyone ever informed you about the possibility of being operated again?Yes No **13. Have you ever had to be operated again due to problems related to the prosthesis?**Yes No If you have answered **"YES"** to question 13, please answer the 3 last questions:

How many times have you been operated again due to problems related to the prosthesis? _____

Which year did you have the second surgery? _____

Indicate why you had to be submitted to the second surgery: _____