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**Conference Theme: Quality versus Cost  
Sustainable Renal Care**

## Burden on informal caregivers of patients on hemodialysis

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# Presentation outline

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# Introduction

- ❑ **The patient in hemodialysis program undergoes significant changes in his quality of life on a physical, emotional and social level, as well as the informal caregiver (IC).**
- ❑ **The IC provides care and assistance to others, but without any payment.**
- ❑ **Generally, this service is provided to a person with whom a relationship already exists. It is an expression of love and care for a family member, friend or simply another human being in need.**

# Objectives

- ❑ **To evaluate the physical, emotional and social burden on informal caregivers (ICs) of patients on hemodialysis at NephroCare Braga.**
- ❑ **To know the level of burden of informal caregiving role in general.**
- ❑ **To verify the relationship among the socio-demographic variables - gender, relationship degree with the patient and the time spent in providing informal care - and the burden on informal caregivers.**

# Methods

- ❑ **This is a correlational, observational and cross-sectional study.**
- ❑ **The material used was a socio-demographic questionnaire (developed by this researcher) and a questionnaire, validated for the Portuguese population, to evaluate the physical, emotional and social burden of the ICs (QASCI).**
- ❑ **The sample consists of ICs of patients on hemodialysis for at least 6 months, non-institutionalized and who wanted to participate in the study.**
- ❑ **For data processing and analysis we used SPSS (Statistical Package for Social Sciences), version 22.0. We conducted descriptive and inferential statistical analysis.**

## QASCI

**This questionnaire is constituted by 7 factors:**

- ❖ **Emotional burden (EB);**
- ❖ **Implications on personal life (IPL);**
- ❖ **Financial burden (FB);**
- ❖ **Reactions to demands (RD);**
- ❖ **Perception of efficiency and control mechanisms (PECM);**
- ❖ **Family support (famS);**
- ❖ **Satisfaction with the role and family (SRF).**

## Descriptive analysis of the burden for ICs in general

	N		Mean	Median	Stand. Deviation	Variance	Min.	Max.
	Valid	Absent						
EB	40	0	35,92	31,58	18,38	337,93	15,79	84,21
IPL	40	0	<b>43,80</b>	41,67	22,53	507,80	7,41	94,44
FB	38	2	32,16	22,22	26,45	699,37	11,11	100,00
RD	39	1	33,01	33,33	16,87	284,49	16,67	83,33
PECM	39	1	31,14	28,57	15,84	251,01	14,29	71,43
famS	39	1	36,75	33,33	27,83	774,31	11,11	100,00
SRF	39	1	29,49	20,83	15,45	238,82	16,67	79,17

0 = absence of burden; 1-25 = light burden; 25-50 = moderate burden; 50-75 = serious burden; 75-100 = extremely serious burden

# Results

## Relation between the socio-demographic variables

### Gender

Factors	Sex	n	Mean Rank	U	p
EB	F	31	21,50	108,500	0.311
	M	9	17,09		
IPL	F	31	21,47	109,500	0.330
	M	9	17,17		
FB	F	30	19,80	111	0.733
	M	8	18,38		
RD	F	30	21,97	76	<b>0,044</b>
	M	9	13,44		
PECM	F	30	19,27	113	0.454
	M	9	22,44		
famS	F	30	21,02	104,500	0.289
	M	9	16,61		
SRF	F	30	20,77	112	0.426
	M	9	17,44		

**\*p<0,05**



# Results

## Relation between the socio-demographic variables

### Degree of kinship

Factors	Degree of kinship	n	Mean Rank	Chi-square	df	p
EB	Spouse	22	18,16	6,56	3	0,087
	Daughter/Son	9	19,78			
	Daughter/Son in law	4	17,13			
	Other	4	33,50			
	Total	39				
IPL	Spouse	22	21,39	5,03	3	0,170
	Daughter/Son	9	14,89			
	Daughter/Son in law	4	15,38			
	Other	4	28,50			
	Total	39				
FB	Spouse	21	21,29	2,91	3	0,406
	Daughter/Son	9	16,50			
	Daughter/Son in law	4	13,75			
	Other	4	22,63			
	Total	38				

**\* $p < 0,05$**

# Results

## Relation between the socio-demographic variables

### Degree of kinship (cont.)

Factors	Degree of kinship	n	Mean Rank	Chi-square	df	p
RD	Spouse	22	17,52			
	Daughter/Son	9	18,28			
	Daughter/Son in law	4	23,38			
	Other	4	34,13			
	<b>Total</b>	<b>39</b>		<b>8,03</b>		<b>0,044</b>
PECM	Spouse	22	20,73			
	Daughter/Son	9	16,33			
	Daughter/Son in law	4	17,25			
	Other	4	27,00			
	<b>Total</b>	<b>39</b>		<b>2,88</b>	<b>3</b>	<b>0,411</b>
famS	Spouse	22	19,27			
	Daughter/Son	9	15,94			
	Daughter/Son in law	4	17,38			
	Other	4	35,75			
	<b>Total</b>	<b>39</b>		<b>9,85</b>		<b>0,020</b>
SRF	Spouse	22	18,39			
	Daughter/Son	9	18,39			
	Daughter/Son in law	4	21,63			
	Other	4	30,88			
	<b>Total</b>	<b>39</b>		<b>4,68</b>	<b>3</b>	<b>0,197</b>

\* $p < 0,05$

# Results

## Relation between the socio-demographic variables

### Time spent on informal care (TSIC)

\* $p < 0,05$

Fatores	TSIC	n	Mean Rank	Chi-square	Df	p
EB	Up to 5 years	18	15,50	3,40	2	0,182
	6 to 10 years	9	23,11			
	> 10 years	9	19,89			
	Total	36				
IPL	Up to 5 years	18	16,25	1,66	2	0,437
	6 to 10 years	9	21,00			
	> 10 years	9	20,50			
	Total	36				
FB	Up to 5 years	18	16,56	1,45	2	0,484
	6 to 10 years	8	17,50			
	> 10 years	9	21,33			
	Total	35				
RD	Up to 5 years	18	14,64	5,16	2	0,076
	6 to 10 years	9	21,44			
	> 10 years	9	23,28			
	Total	36				
PECM	Up to 5 years	18	16,14	1,90	2	0,386
	6 to 10 years	9	20,67			
	> 10 years	9	21,06			
	Total	36				
famS	Up to 5 years	18	15,06	36,21	2	<b>0,044</b>
	6 to 10 years	9	18,56			
	> 10 years	9	25,33			
	Total	36				
SRF	Up to 5 years	18	15,17	4,06	2	0,132
	6 to 10 years	9	22,78			
	> 10 years	9	20,89			
	Total	36				

**ICs feel physical overload, emotional changes and limitations on their social life. As there is a demand on psychological coping mechanism, a psychological intervention to lessen ICs perceived burden is important.**

# Thank You Very Much for Your Attention!

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