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Overload questionnaire for caregivers of patients on peritoneal dialysis

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SUMMARY

Introduction: *Despite the interest generated by the increasing number of studies that measure Quality of Life among patients and caregivers, few of these studies measure the caregivers burden in Peritoneal Dialysis (PD).*

Objective: *The main target of this study was to create a burden measure questionnaire applicable amongst caregivers of PD patients.*

Methodology: *Inclusion criteria: 1) Patients had to be in PD treatment for more than 3 months; 2) Patients had to receive help with the PD treatment from a caregiver. The study was divided into 3 phases:1st) design and use of the initial questionnaire; 2nd) a test-retest on a modified scale; and 3rd) to provide the questionnaire-3 to two collaborative centres with similar PD programs. Four groups of caregivers were established: A1:23, A2:17, B:7 and C:16 caregivers. We applied 5 scales (S): 1- Patient Dependence on caregiver, from caregivers' view (D); 2- Complete caregiver burden (CB), including 12 items which measure the caregivers' subjective burden, 3- Reduced caregiver burden (RB), as the one before but with only 8 items, 4- Repercussions on the caregiver (R), which measures objective burden; 5- Specific PD tasks (ST), a scale that measures the effort the tasks implied in the PD treatment represent for the caregiver.*

Results: *We studied 63 caregivers (table I): mean age: 53.43 (SD = 12.3); Sex: Females: 86.4%, Males: 13.6%, corresponding to 63 patients: mean age: 59.79 (SD = 15.9); Sex: Males: 80.3%, Females: 19.7%.*

Valuable results for reliability, unidimensionality, and discrimination were obtained in the 1st and 2nd phases, except for burden scale which was compound of two factors; then one of those factors was suppresed. In the 3rd phase, ANOVA did not show any differences between centres (table II). Consequently, all caregivers could be analysed together. Reliability results for each one of the third phase scales (table III) were: D: Cronbach α = 0,886; CB: α = 0,894; RB: α =0,857; R: α = 0,892; ST: α = 0,62. Although the ST scale obtained an acceptable reliability, it was suppresed in the 3rd phase due to the low correlation with other scales and the fact that it was not applicable to all caregivers. Finally, a direct correlation was found between third phase scales (table IV): D-RB: r = 0.502, $p \leq 0.001$; D-R: r = 0.599, $p \leq 0.001$; RB-R: r = 0.775, $p \leq 0.001$. We must headlight that both Burden scales, and the Repercussion scale, obtained a direct correlation with the Dependency scale.

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Conclusion: *A questionnaire has been created to measure burden and repercussions on caregivers of peritoneal dialysis patients. It can already be applied, as requirements of both reliability and validity are fulfilled. This questionnaire can be a useful tool to prevent caregivers' burnout.*

Key words: ***Caregiver. Questionnaire validation process. Peritoneal dialysis. Dependency scales. Burden and Repercussion.***

CUESTIONARIO DE SOBRECARGA DE CUIDADORES DE PACIENTES DE DIÁLISIS PERITONEAL

RESUMEN

Justificación: *En Diálisis Peritoneal pocos estudios miden la sobrecarga del cuidador.*

Objetivo: *proporcionar una herramienta de medida de sobrecarga aplicable a cuidadores de pacientes en Diálisis Peritoneal.*

Material y métodos: *Condiciones de inclusión: 1) mínimo 3 meses en tratamiento; 2) participación del cuidador. Estudio dividido en 3 fases: 1) cuestionario inicial; 2) test-retest; 3) administración del cuestionario-3 a 2 centros colaboradores. Se establecieron 4 grupos de cuidadores: 2 del hospital A: A1: n = 23, A2: n = 17; B: n = 7, C: n = 16. Se aplicaron 5 escalas: 1- Dependencia del paciente, 2- Sobrecarga del cuidador completa, 3- Sobrecarga del cuidador reducida, 4- Repercusiones sobre el cuidador, 5- Tareas específicas de Diálisis Peritoneal.*

Resultados: *Estudiados 63 cuidadores, edad: 53,43 (SD = 12,3); 86,4% mujeres, 13,6% hombres correspondientes a 63 pacientes, edad: 59,79 (SD = 15,9); 80,3% hombres, 19,7% mujeres. En fases 1 y 2, se obtuvieron fiabilidades y unidimensionalidades elevadas de cada escala y discriminaciones adecuadas de los ítems de cada escala, excepto en la escala de sobrecarga que resultó estar compuesta por dos factores, por lo que se eliminó uno de ellos. En la fase 3, la ANOVA no mostró diferencias entre centros, por lo que todos los cuidadores se analizaron conjuntamente. Fiabilidad de las escalas-3: Dependencia: α de Cronbach = 0,886; Sobrecarga Completa: $\alpha = 0{,}894$; Sobrecarga Reducida: $\alpha = 0{,}857$; Repercusiones: $\alpha = 0{,}892$; y Tareas específicas: $\alpha = 0{,}620$. La Escala de Tareas específicas, con moderada fiabilidad, guardó baja relación con las escalas anteriores y no fue aplicable a todos los cuidadores; por ello se suprimió en la fase 3. Hubo correlación positiva moderada entre las escalas-3: Dependencia-Sobrecarga Reducida: r = 0,502, p = < 0,001; Dependencia-Repercusiones: r = 0,599, p = < 0,001; Sobrecarga Reducida-Repercusiones: r = 0,775, p = < 0,001, siendo destacable que las escalas de Sobrecarga y la de Repercusiones tuvieron correlación positiva y elevada con la de Dependencia.*

Conclusión: *Se ha creado un cuestionario para medir la sobrecarga y repercusiones, en los cuidadores de pacientes de Diálisis Peritoneal, que cumple con los requisitos de fiabilidad y validez para ser aplicado. Puede ser una herramienta útil en la prevención del agotamiento del cuidador.*

Palabras clave: ***Cuidadores. Validación cuestionario. Diálisis peritoneal. Escalas de dependencia. Sobrecarga y Repercusión.***

INTRODUCTION

Peritoneal dialysis is a renal replacement therapy appropriate for individuals of any age that suffer from end-stage chronic renal failure.[1] Two of the more relevant features of this therapy are its good tolerability and being a home-based therapy, which makes it applicable not only to patients independent in their daily living activities and responsible of their own treatment, but also to patients partially or totally dependent. Many of these patients are aged or elderly people,[3-6] or may be young people with physical or mental disabilities that require the aid of a caregiver for daily living activities. In all cases, the caregiver role is essential to carry out renal replacement therapy with peritoneal dialysis (PD).

In recent years, the study of overload and impact on quality of life of caregivers has become more relevant in chronic diseases such as dementia, Alzheimer's disease, cancer,[7] other pathologies requiring palliative care,[8] rheumatoid arthritis,[9] and gerontology,[10] at the same time that caregiver recovery programs have been implememtned.[11] However, these issues have been less studied in caregivers of dialysis patients.

For hemodialysis (HD), the caregiver quality of life has been assessed through questionnaires about partner relationship[12-14] tests for measuring anxiety, personality, depression, vital satisfaction, and family stress,[15] and health and quality of life questionnaires (*Short Form Health Survey SF-36*). Caregivers overload of HD patients has been studied in few works.[15-17]

In PD, patient's[18-19] and caregiver's quality of life has been studied by means of questionnaires focused on impact on marital life,[12,13,20,21] or by psychosocial impact on family members of diseased children.[22,23] Watson found higher treatment-related overload in families of children on PD as compared to those patients on HD or renal transplantation (RT).[23] This is in agreement with previous observations on the risk of overload or quality of life impairment of family members of patients on PD.[20] However, other studies have not found significant differences between HD or PD caregivers.[17,18,21]

Since many patients on PD require a caregiver to take care of them, either because of these patients' dependency for daily living activities or because of the need for help with dialysis therapy, it seems reasonable to perform a study on caregiver's overload with a specific questionnaire on peritoneal dialysis. We have not found such a questionnaire reviewing the available literature.

This work presents the proceedings of elaborating and validating an overload questionnaire for caregivers of patients on peritoneal dialysis.

MATERIAL AND METHODS

Inclusion criteria for caregivers were: a) the patient has to be for at least 3 months on PD; and b) the role of primary caregiver has to exist. Primary caregiver was defined as that person close to the patient that, being questioned, confirms that he/she assumes responsibility of care of the patient on PD.

This validation study comprised 3 phases:

1) Elaboration of the initial questionnaire and application to the first group of caregivers.

2) Modification of the overload scale and performance of a test-retest of the scale and analysis of further temporal reliability

3) Administration of the questionnaire-3 to caregivers of the two centers collaborating with PD programs and final comparative analysis for the questionnaire validation.

Four study groups and four dependent variables were established for statistical analysis of the final study phase.

Groups

1. Hospital **A1**: a group of 23 caregivers interviewed with the initial questionnaire.
2. Hospital **A2**: a group of 17 caregivers for test-retest of the Overload Scale.
3. Hospital **B**: a group of seven caregivers interviewed with the final questionnaire.
4. Hospital **C**: a group of 16 caregivers interviewed with the final questionnaire.

Dependent variables

1. «Dependency Scale» (D) of the patient, according to caregiver with eight items.

2a. «Complete Caregiver Overload Scale (COS)» with 12 items that measure subjective caregiver overload.

2b. «Reduced Caregiver Overload Scale (ROS)» that includes only 8 items from the complete scale.

3. «Socio-familial impact on caregiver scale (IS)» with 10 items related to the objective overload on the caregiver.

4. «Caregiver's endeavor in specific PD tasks Scale (STS)» with a varying number of items depending on PD modality: Continuous Outpatient Peritoneal Dialysis (3 items) or Automated Peritoneal Dialysis (4-5 items).

For data statistical analysis we used: the Cronbach's alpha coefficient for reliability and internal consistency, unidimensionality tests for each scale, analysis of discrimination capability of each item and factorial analysis for each COS scale by means main components extraction procedure (ACP), Pearson's correlation for correlation analysis between the different scales, and one-factor ANOVA for mean scores comparison between groups.

The study was approved by the Hospital Ethical and Research Committee. All patients and caregivers were informed and informed consent was obtained to participate in the study.

RESULTS

The characteristics of caregivers included, distributed by health care facility, are shown in Table I.

Eighty-two point five percent of patients were male, whereas 87.3% of caregivers were female. Caregivers' mean age was: 50.65 (SD = 11.08), which slightly lower than that of patients: 56.97 (SD = 14.79), with a small difference, and most of the caregivers were the spouses.

There were no significant differences in patients and caregivers characteristics by health care facility of origin.

1st phase: From de dependency and overload features that caregivers of patients in our peritoneal dialysis program usually report we drafted a list of questions focused on 3 sections: 1) patient's dependency seen from the caregiver point of view; 2) overload perceived by caregiver, including negative and positive aspects that would compensate this overload; 3) impact on caregiver on issues such as family,

Table I. General characteristics of patients and caregivers. By centers

Center	**A1**	**A2**	**B**	**C**	**ALL**
PATIENTS: n	**23**	**17**	**8**	**18**	**63**
AGE (1)	57.74 (15.18)	53.82 (14.6)	57.43 (13.79)	59.0 (15.64)	56.97 (14.79)
GENDER					
male	17 (73.9%)	15 (88.2%)	6 (85.7%)	14 (87.5%)	52 (82.5%)
female	6 (26.1%)	2 (11.8%)	1 (14.3%)	2 (12.5%)	11 (17.5%)
MODALITY					
COPD (2)	4 (17.4%)	2 (11.8%)	2 (28.57%)	3 (18.8%)	11 (17.46%)
APD (2)	19 (82.6%)	15 (88.2%)	5 (71.42%)	13 (81.3%)	52 (82.53%)
CAREGIVERS					
AGE (1)	50.04 (10.73)	50.53 (11.3)	49.86 (10.73)	52.0 (12.33)	50.65 (11.08)
GENDER					
male	3 (13%)	2 (11.8%)	1 (14.3%)	2 (12.5%)	8 (12.7%)
female	20 (87%)	15 (88.2%)	6 (85.7%)	14 (87.5%)	55 (87.3%)
KINSHIP					
Son/daughter	1 (4.3%)	1 (5.9%)	1 (14.3%)	2 (12.5%)	5 (7.9%)
spouse	17 (73.9%)	15 (88.2%)	6 (85.7%)	12 (75%)	50 (79.4%)
parent	5 (21.7%)	1 (5.9%)	0	1 (6.3%)	7 (11.1%)
other	0	0	0	1 (6.3%)	1 (1.6%)
OCCUPIED					
yes	11 (47.8%)	8 (47.1%)	4 (57.1%)	9 (56.3%)	32 (50.8%)
no	12 (52.2%)	9 (52.9%)	3 (42.9%)	7 (43.8%)	31 (49.2%)
TIME HELPING WITH PD					
< 6 months	2 (8.7%)	2 (11.8%)	2 (28.6%)	1 (6.3%)	7 (11.1%)
6 m-1y	4 (17.4%)	3 (17.6%)	1 (14.3%)	3 (18.8%)	11 (17.5%)
1-2 y	12 (52.2%)	8 (47.1%)	1 (14.3%)	4 (25%)	25 (39.7%)
2-3 y	3 (13%)	3 (17.6%)	1 (14.3%)	3 (18.8%)	10 (15.9%)
> 3 y	2 (8.7%)	1 (5.9%)	2 (28.6%)	5 (31.3%)	10 (15.9%)
HOME					
Same home	19 (82.6%)	17 (100%)	7 (100%)	16 (100%)	59 (93.7%)
Same building	1 (4.3%)	0	0	0	1 (1.6%)
Different town	3 (13%)	0	0	0	3 (4.8%)

Notes: (1) Age expressed as mean (standard deviatiion). (2) COPD: Continuous Outpatients Peritoneal Dialysisç APD: Automated Peritoneal Dialysis.

job, hobbies, spare time, all of them related to peritoneal dialysis. A fourth section was added aimed at assessing dedication and duty for specific peritoneal dialysis-related tasks. All this comprised the initial survey.

The initial questionnaire was administered to 23 caregivers from group A1.

1. The patient's dependency scale, with nine items showed the optimal reliability (α coefficient = 0.885) and appropriate unidimensionality and discrimination, except for one item that was further deleted.
2. The caregiver's overload scale, with 12 items, had a fair reliability (α = 0.720). However, large variability in the discrimination degree of each element was observed. The multifactorial analysis allowed deleting one item with no discriminating value and finding that the scale was composed by two different overload factors or dimensions. The items grouped as factor 1 measured positive feelings from satisfaction derived from supplying help to the patient. The factor-2 items measured negative or tiredness feelings derived from the same type of help. There was a direct correlation between factor 2 and the patient's dependency scale. Consequently,factor-1 items were erased and the scale was modified to analyze only one dimension based on factor 2.
3. Socio-familial impact on the caregiver, with 11 items relating to caregiver's social and occupational life and spare time. Reliability was optimal (α = 0.847) and discrimination fair but for one element that was further deleted. Correlation with dependency was moderate ($r = 0.522$, $p = 0.011$) and high with factor 2 of overload ($r = 0.737$, $p < 0.001$).
4. Caregiver's endeavor in peritoneal dialysis-related tasks scale: four items were analyzed in this section that had a moderate reliability (α = 0.62) and marked unidimensionality and discrimination, but low or none relationship with the previous scales. Thus, this section was deleted from further study phases.

2^d phase: The caregiver's overload scale was modified, now compounded by 14 items (four out of 12 items were initially modified and 2 more were modified), and was administered to 17 caregivers already interviewed during the first phase as test-retest with an interval of 4 to 7 months. The reliability analysis was fair (_ = 0.81) but in the unidimensional and discrimination analyses and homogeneity analysis for each item with the whole scale it was found that two items were not discriminative, so that they were erased and the scale contained again 12 items. The correlation of the seven concurrent items in the test-retest analysis was moderate ($r = 0.512$) and statistically significant ($p = 0.036$) for an _ level of 0.05.

3^d Phase:

All items of the different scales were structured for 5-categories Likert-type answers. Table II shows he results of the three scales by centers. There were no statistical significant differences by centers. The reliability analysis of the three scales of the 3^d phase with all caregivers pooled is shown in Table III, α coefficients being high (0.86-0.89).

All correlation coefficient between the four scales were positive (r comprised between 0.42-0.97), and statistically highly significant (p comprised between 0.008 and < 0.001). Besides, the overload and impact scales having a significant correlation with the patient's dependency scale, the whole value of the questionnaire and the validity of each one of these scales are strengthen.

Table IV shows the correlation matrix between the studied scales.

Construction of reckoners: From the data available we have constructed provisional reckoners corresponding to the three scales of the third phase. For the overload scale, the 17 caregivers that had done the test-retest, with concurrent items, had been added to the 38 caregivers that answered the questionnaire, so that the number of useful questionnaires is 55 (Table V). These reckoners will have to be rebuilt in the future when administering the questionnaires to a larger and more representative sample.

DISCUSSION

We have elaborated a questionnaire to measure PD patients caregiver's overload that includes a patient's dependency scale according to the caregiver's perspective, a subjective caregiver's scale, an objective caregiver's scale that assesses the objective overload based on repercussions that limit caregiver's social and occupational life and spare time.

The internal consistency, as shown by the reliability analysis with Cronbach's α coefficient was high

Table II. Scores for the Dependency, Overload, and Impact scales. Comparison between centers

Center	A1	A2	B	C	ANOVA
n =	23	17	7	16	p =
Dependency	20,91(9,94)	19,76 (9,32)	22,14 (6,79)	27,69 (8,29)	0,069
Overload R.	15,04 (5,71)	13,0 (5,21)	14,43 (6,71)	15,86 (8,82)	0,650 (1)
Overload C.	- (-)	18,94 (6,94)	22,29 (9,59)	23,50 (11,46)	0,387 (2)
Impact	23,09 (9,16)	23,41 (9,73)	23,29 (10,61)	25,56 (12,19)	0,892

* Notes: (1): R. = Reduced with 8 items. (2): C.= Complete with 12 items.

Table III. Reliability analysis of scales of the third phase

Scale	Items	Cases	α Coeff.
Dependency	8	63	0.8860
Overload R.	8	61	0.8577
Overload C.	12	38	0.8943
Impact	10	63	0.8926

or fair for the third study phase, indicating that the questionnaire meets the reliability criteria for its implementation.

The results obtained by comparing the data from the different participant centers do not show significant differences, so that it may presume that all cases come from a similar population and a pool analysis can be made.

The unidimensionality analysis and the discrimination capability analysis have allowed for the determination of some items initially included that shared a low relationship with the remaining items of the scale.

The test-retesting of the overload scale in the second phase was done with some limitations such as: a) it was only applied to the 7 items that did not vary between the first and second phases; b) it was administered only to 17 out of the 23 initial caregivers.; and c) the time interval was between 4-7 months, during which the overload conditions might have varied for some caregivers. Therefore, the temporal stability of the scale was moderate although acceptable since the correlation was statistically significant for an α level of 0.05 but the correlation was not too high (r = 0.512). It was considered sufficient since it was not a final scale that is pending to be applied on a larger and more representative sample.

The endeavor on performance of peritoneal dialysis tasks (STS) was initially included as a specific and

Table IV. Correlation matrix between dependency, overload and impact scales (1)

	Dependency	Overload R. (2)	Overload C. (3)	Impact
Dependency	1	0,502	0,424	0,599
(p =)	..	(< 0,001)	(= 0,008)	(< 0,001)
Overload R. (2)		1	0,972	0,775
(p =)		..	(< 0,001)	(< 0,001)
Overload C. (3)			1	0.748
(p =)			..	(< 0,001)
Impact				1
(p =)				..

* Notes: (1): Correlation coefficient r = .. (p = ..). (2): Overload Reduced, with 8 items. (3): Overload Complete with 12 items.

Table V. Construction of reckoners

		Total scale dependency	Total scale overload	Total scale impact
N	valid	63	55	63
	lost	0	8	0
Mean		22.46	20.53	23.83
Media		19.0	17.0	19.0
St. deviation		9.408	8.641	10.107
Percentiles	10	11.0	13.0	13.0
	20	14.0	15.0	14.0
	30	15.0	16.0	16.0
	40	16.0	16.0	18.0
	50	19.	17.0	19.0
	60	26.0	18.0	24.0
	70	28.0	21.0	29.0
	80	33.0	25.0	35.0
	90	37.0	39.0	39.0

concrete measure of the capability of producing caregiver's overload. Although this scale had a moderate or fair reliability, it also had a low number of responses because the items did not apply to all cases due to differences in therapy modalities (COPD and APD) and because not all caregivers did the same PD tasks.

Besides, the answers of those caregivers completing the scale had a low correlation with the caregiver's overload scale and with the patient's dependency scale. This suggests that PD tasks do not have a relationship with the caregiver's overload but that the latter is derived from the patient's dependency and from how the caregiver and the patient feel the responsibility of renal replacement therapy.

Letting out the task scale does not alter or decrease the objective of measuring the PD caregiver's overload because all the other questions from the other scales of the questionnaire refer to the impact of peritoneal dialysis.

Indeed, the main difference of these 2 scales (overload and impact) with the other overload scales applicable to any caregiver population is that the wording of each item limits the relationship of the caregiver's overload or repercussion to the specific tasks of peritoneal dialysis.

If a general overload scale is applied, with no specific mentioning to PD, we would obtain answers induced by the different co-morbid events that are commonly associated in these patients, which would not be adequate for the purpose of this study.

The quality of life of patients on renal replacement therapy has been studied in many works in the literature, either by comparing the quality of life of the hemodialyzed patient with that of the peritoneal dialysis patient,[17-19,24-28], or by studying the transplanted patient.[29]

Most of the studies on caregivers of dialysis patients (either HD or PD) have used general questionnaires such as general health, marital relationship,[17,19-21,24,25], depression, anxiety, or quality of life, applicable to several populations but not specifically referred to dialysis therapy. One work even applied a specific scale for multiple sclerosis patients («The Fatigue Severity Scale») to caregivers of patients treated for CRF.[30] The outcomes showed a high level of physical fatigue and overload in caregivers, but the fact of applying a scale designed for a diseased population to a theoretically healthy population may have conditioned the resulting outcomes.

Caregivers of PD patients may feel overloaded by patient's dependency and his/her disease, besides of the specific tasks of PD. Thus, we have considered that a specific questionnaire, such as the one presented, was necessary. However, our preliminary data of the task scale did not show correlation with the patient's dependency scale or with the subjective or objective overload scales. Therefore, it may be considered that the general overload scale, unspecific for PD, would be sufficient to quantify the degree of caregiver's overload. There are no enough data on this issue, so that it is worth studying this issue on more detail by applying global and specific questionnaires to assess the disease-related and PD-related overload.

To conclude, it may be stated that although more studies are required to confirm the clinical application of this questionnaire, this is a tool that may be useful to measure the degree of overload and impact of caregivers of PD patients; it allows scientifically studying this issue, establishing clinical action criteria, and possibly preventing the caregiver's exhaustion, by preventing him/her to reach a «burn-out» condition, that is to say, a no-way back situation.

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ANNEX 1. Overload questionnaire for caregivers of patients on peritoneal dialysis

The subject on peritoneal dialysis therapy:

1. Does he/she go out?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Very often

2. Does he/she need help moving around?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

3. Does he/she do any housekeeping task?
☐ None ☐ Some ☐ Several ☐ Many ☐ All

4. Does he/she need help with personal cleanliness?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

5. Does he/she need help for relieving him/herself?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

6. Can he/she be left alone and for 2-3 hours a day?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

7. Can he/she be left alone all nigh long?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

8. Should be there any troubles with dialysis, does he/she seek your help to solve them?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

To what extent have yor felt the following statements?

9. Since I have to help with dialysis, everything gets me out of myself?
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

10. Since I am in charge of peritoneal dialysis, I have sleeping troubles
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

11. Having to help with dialysis makes me feel more tired day by day
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

12. When I think that peritoneal dialysis has to be done every day I feel gloomy
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

13. When I look at the person I take care of connected to peritoneal dialysis I think life is not worth living
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

14. When a trouble arises, such a catheter infection, I cannot stop thinking what I have made wrong
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

15. Since I am in charge of peritoneal dialysis, I have the feeling of being overwhelmed with all thigs I have todo
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

16. Since I take care of the person on peritoneal dialysis, I do not feel like going out or having fun
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

17. Since I help with peritoneal dialysis, I do not look ahead with hope
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

18. I get angry when the person on peritoneal dialysis does not do things correctly
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

19. Since I help with peritoneal dialysis, I am not able to show affection
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

20. Since I help with peritoneal dialysis, I feel anguished having to face other problems
☐ Never ☐ Sometimes ☐ Several times ☐ Many times ☐ Always

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ANNEX 1. Overload questionnaire for caregivers of patients on peritoneal dialysis

Answer now this new set of questions

21. To what extent does helping with peritoneal dialysis impact on your working life?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

22. To what extent have you had to modify or adapt your holidays for helping with dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

23. To what extent has the fact of you helping with peritoneal dialysis impacted on your family life?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

24. To what extent has your social life being altered since you help with peritoneal dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

25. To what extent have you modified or adapted your hobbies for helping with peritoneal dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

26. To what extent has your own health been affected because of helping with peritoneal dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

27. To what extent would you say that your family members feel affected by you being in charge of peritoneal dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

28. Since you are in charge of peritoneal dialysis, to what extent do you feel completely responsible of the health and well being of the person you take care off?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

29. To what extent have you had to modify or readapt your schedules because of peritoneal dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

30. To what extent are you directaly affected by cleansing demands related with peritoneal dialysis?
☐ Not at all ☐ A little bit ☐ Quite a bit ☐ A lot ☐ Completely

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