Association Between Urinary Incontinence in Elderly Patients and Caregiver Burden in the City of Sao Paulo/ Brazil: Health, Wellbeing, and Ageing Study

José Tadeu Nunes Tamanini,[1]* Jair L.F. Santos,[2] Maria Lúcia Lebrão,[3] Yeda A.O. Duarte,[4] and Ruy Laurenti[3]

[1]*Departamento de Medicina, Centro de Ciências Biológicas de da Saúde, Universidade Federal de São Carlos, SP, Brazil*
[2]*Faculdade de Medicina de Ribeirão Preto, Departamento de Medicina Social, Universidade de São Paulo, SP, Brazil*
[3]*Faculdade de Saúde Pública, Universidade de São Paulo, SP, Brazil*
[4]*Escola de Enfermagem, Universidade de São Paulo, SP, Brazil*

Aim: Some elderly patients with incontinence require the care of third parties, known as caregivers. Such care can occur on a daily basis leaving little opportunity for the caregiver to take care of himself/herself. The aims are to assess the association between urinary incontinence in elderly patients and caregiver burden and identify independent factors for caregiver's burden in the city of Sao Paulo, Brazil. **Methods:** The Pan-American Health Organization and World Health Organization coordinated a multicenter study named Health, Wellbeing and Aging (SABE Study) in elderly people living in seven countries of Latin America and the Caribbean. In Brazil, the study population carried out in São Paulo in the year 2000 and reassessed in 2006 (COHORT A). Urinary incontinence was assessed by ICIQ-SF and caregiver burden by means of Zarit Burden Scale. **Results:** A total of 327 patients with caregivers were included in the study. The general prevalence of urinary incontinence was 25.8%, higher among the women. There was a significant positive association between caregiver burden and incontinent patients, demonstrating that urinary incontinence in elderly patients produced greater caregiver burden. In the present study, the variables with significant correlations were assessed using the multivariate logistic regression model. Category 2 of the ICIQ-SF (incontinent patients) increased the chances of caregiver burden 1.96-fold in comparison to Category 1 (continent patients). Likewise, the category of impaired cognition increased the chances of caregiver burden 2.34-fold. **Conclusions:** Urinary incontinence and cognitive impairment in elderly patients were associated to an increase in caregiver burden. *Neurourol. Urodynam. 30:1281–1285, 2011.* © 2011 Wiley-Liss, Inc.

Key words: ageing; ICIQ-SF, SABE Study; urinary incontinence; Zarit Caregiver Burden Scale

INTRODUCTION

When a person experiences illness, regardless of type or severity, the impact is not isolated to the affected individual. The implications of illness are felt throughout a person's immediate social network, specially the individual's immediate family and partner/spouse.[1] In this scenario urinary incontinence (UI) is a stressful, debilitating condition and a factor of social isolation that has a negative effect on quality of life and self-esteem and is commonly found among elderly individuals. The prevalence of UI among the elderly (>60 years) in Brazil is reported to be 11.8% among men and 26.2% among women.[2] Some elderly patients with incontinence require the care of third parties, known as caregivers. Such care can occur on a daily basis, taking up much of the caregiver's time and leaving little opportunity for the caregiver to take care of himself/herself or get proper rest.

Furthermore, the need to provide care to incontinent elderly patients may occur in a sudden fashion and this care is often offered without the preparation of the caregiver, which can lead to insecurity and anxiety, thereby generating physical and mental stress. Another important factor with regard to caregiver burden is the fact that the caregiver is obliged to deal with activities that involve the immediate interaction with the patient, such as giving support to patient hygiene, changing diapers/absorbent pads, and being exposed to contact with urine and feces. Incontinence may also affect conjugal relations, transforming the spouse into a caregiver, with a negative effect on the intimacy and sex life of the couple.[3] In the health field, there is growing interest in the relationship between patient and caregiver and the consequences of this relationship. However, there are few studies that specifically address UI and its association with caregiver burden. The aim of the present study was to assess the association between UI in elderly patients and caregiver burden in the city of Sao Paulo, Brazil.

MATERIALS AND METHODS

The Pan American Health Organization (PHO) and World Health Organization (WHO) coordinated the multi-center Health, Wellbeing, and Ageing Study, denominated the SABE Study to assess the living condition of elderly individuals in seven countries in Latin America and the Caribbean (Argentina, Barbados, Brazil, Chile, Cuba, Mexico, and Uruguay). In Brazil, the population studied was made up of elderly individuals (over 60 years of age) in the city of Sao Paulo in the year 2000, who were reevaluated in 2006.[4] The SABE Study received approval from the Ethics Committee of the *Universidade de São Paulo* and *Conselho Nacional de Ensino e Pesquisa*. The initial sample of 2,143 individuals was made up of two segments. The first was the result of selection by lots and corresponded to a probabilistic sample formed by 1,568

interviewees. The second was formed by 575 residents in the districts of Sao Paulo who were submitted to the same interview and corresponded to an increase to compensate for the death of individuals over 75 years of age and complete the desired number of interviews in this age group. Sampling by conglomerates was used for the selection of residences by lots, carried out in two stages using the partition criterion proportional to size. A permanent registry of 72 census sectors at the Epidemiology Department of the School of Public Health was considered the first-stage sample. This sample was taken from the records of the National Domicile Sample Survey (1995), made up of 263 census sectors selected by lots using the probability criterion proportional to the number of residences. The minimal number of residences in the second stage was estimated as 90. The complementation of the sample with individuals aged 75 years or more was performed with residences near the selected sector or at least within the limits of the districts to which the selected sectors belonged.

Each questionnaire had a weight calculated based on the census sector to which it belonged (weight = 1/f). For the questionnaires of individuals from residences that were selected but not randomly determined by lots (75 years or older), the calculation of weight was determined in relation to the elderly population in this age group in the city of Sao Paulo in 1998 and the number of individuals in this age group in the final sample of the study.[5]

A detailed description of the methodology employed can be found at http://www.opas.org.br/publicmo.cfm?codigo=70 (last accessed on January 26, 2009).

The study was replicated in a second round held in 2006, thereby transforming it into a longitudinal study. In this phase, the individuals interviewed in the year 2000 were interviewed a second time. A search for obituaries between 2000 and 2006 was first carried out using the databases of the SEADE Foundation and PROAIM with a comparison of names, addresses, gender, and date of birth. To locate the surviving individuals, the addresses on the original questionnaires were used and confirmed by team of assistants. For those not located through their original address, a search for information was made in the neighborhoods (surrounding streets, pharmacies, markets, churches, etc.) and complementary data on the base questionnaire (telephone numbers for contact, offspring or other relatives). Print media was used to help locate the remaining individuals. After the intensive search, the sample was considered closed and the individuals not found were denominated "not located."[6]

Individuals were located and interviewed using sections A (personal data), C (health status), N (caregiver burden), and K (anthropometry) on the data collection instrument.

Scales, Questionnaires, and Definitions

The scales, questionnaires, and UI definition employed in the present study are widely used in clinical research.

This study uses the definition of the International Continence Society for UI (suitable for epidemiological studies), which is the complaint of "any involuntary loss of urine"[7] and the International Consultation on Incontinence Questionnaire—Short Form (ICIQ-SF), which has been validated for Portuguese.[8]

UI was the dependent variable and has two response options based on the ICIQ-SF, which assesses the presence and impact of UI on quality of life. The ICIQ-SF score ranges from 0 to 21, for which higher scores denote a greater impact of UI. Patients with a score of 0 were considered not to have UI and those with scores 1 and higher were considered to have UI.

Caregiver burden was assessed using the Zarit scale, which has 22 questions on the impact of the disorders of patients on the quality of life of their caregivers. For each item, the caregivers were instructed to indicate the degree of burden taking care of debilitated or ill individuals could cause, with five response options: never, rarely, sometimes, often, and always. The score of each response ranged from 0 (never) to 4 (always). The total score ranged from 0 to 88, with higher scores denoting a greater degree of caregiver burden. Caregivers with scores of 28 points or less were considered to have no burden and those with scores of 29 points or more were considered to have burden. The cutoff point was determined by a sensitivity and specificity study on the Zarit scale, which indicated that this cutoff point would produce the greatest percentage of correct classifications. The Zarit questionnaire addresses aspects that are more frequently affected and reported by caregivers, such as health, psychological wellbeing, finances, social life, and relationship with the patient. The scale has been validated for Portuguese.[9,10] The Mini-Mental State Exam (MMSE) was used for the cognitive assessment of the elderly individuals' cognitive state.[11] This instrument is used for the screening and evaluation of cognitive disorders. The score ranges from 0 to 30, with lower scores denoting greater cognitive impairment. Depending on the degree of schooling, scores below 24 points are considered abnormal.

The hypothesis to be tested in the present study was that UI of the patient would be associated to an increase in caregiver burden and the independent variables on the patient (socio-demographic, clinical, and functional variables) would have an influence over this increase in caregiver burden. Unanswered questions and responses of "I don't know" were considered missing values.

Statistical Analysis

Descriptive analysis was performed on the characteristics of the sample, comparing mean Zarit scores (caregivers) and presence/absence of UI, cognitive deficit, functional alterations in the performance of basic/instrumental activities of daily living (BADL and IADL), gender and age (patients). The Rao–Scott test was used for the determination of the association of the Zarit scale with the ICIQ-SF and MMSE scores. Spearman's correlation test was used for the statistical determination of the possible association between the scores on the Zarit scale and ICIQ-SF final score.

The Wald test for mean values in complex samples[12] was used to determine associations between the mean scores of each question on the Zarit scale and continent (ICIQ-SF = 0) and incontinent (ICIQ-SF $\geq$ 1) patients.

Both Wald[12] and Rao–Scott[13] tests were used in place of the usual chi-square and *t*-tests due to the sample design: chi-square and *t*-tests are not to be used in samples with unequal probabilities of selection.

Following the initial analysis, multivariate logistic regression was performed, with the level of significance set at $P < 0.05$. The STATA program (version 10.0) was used for all statistical calculations.

RESULTS

The sample of the present cross-sectional study was taken from the 1,115 patients of the SABE Study/2006 (Cohort A—2006), of whom 327 had caregivers and answered the ICIQ-SF. Among the total of patients included, 101 (31%) were male and 226 (69%) were female. When compared to the sample weights, these values corresponded to population estimates of 39% and

TABLE I. Distribution of Elderly Individuals According to Socio-Demographic and Clinical Variables; City of Sao Paulo, SP, Brazil, 2006 (n = 327)

Socio-demographic variables	%
Age group	
60 to 74 years	84
75 years or more	16
Gender	
Male	31
Female	69
Urinary incontinence (final ICIQ-SF score)	
ICIQ-SF = 0 (continent)	74.2
ICIQ-SF ≥ 1 (incontinent)	25.8
Functional state	
Difficulties in BADL	26.6
Difficulties in IADL	73.2
Mental state (MMSE)	
Cognitive alteration	14.9
No cognitive alteration	85.1

61%, respectively. The general prevalence of UI was 25.8% and higher among the women. The distribution of elderly individuals according to socio-demographic and clinical variables are presented in Table I.

Correlation Study

Although weak, the correlation between the mean scores on each question of the Zarit scale and the ICIQ-SF final scores was significant (Spearman's correlation coefficient = 0.14; $P = 0.011$; n = 327), demonstrating that a greater impact of UI on the patient denotes greater caregiver burden.

The variables with significant correlations ($P < 0.05$) were assessed using the multivariate logistic regression model. Category 2 of the ICIQ-SF (incontinent patients) increased the chances of caregiver burden 1.96-fold ($P = 0.022$) in comparison to Category 1 (continent patients). Likewise, the category of impaired cognition increased the chances of caregiver burden 2.34-fold ($P = 0.006$) (Table IV). No associations were found between the dependent variables (Zarit score up to 28 and Zarit score of 29 or more) and the independent functionality variables of the patients, such as basic activities of daily living ($P = 0.39$). There were also no significant associations between the score on the Zarit scale and age group ($P = 0.68$) or gender ($P = 0.49$).

Association Studies

Associations between the classes of scores on the Zarit scale and ICIQ-SF final scores were analyzed (Table II). The same was done with the classes of scores on the Zarit scale and MMSE (Table III). The mean scores on each question of the Zarit scale were compared between the classes of continent and incontinent patients (Fig. 1).

DISCUSSION

Situations of chronic debility in health, such as the frailness of elderly individuals and the reduction in cognitive function and/ or functional state, may have negative repercussions on the health and wellbeing of family caregivers. Recent studies have demonstrated that between 40% and 70% of caregivers exhibit symptoms of clinical depression and approximately 50% exhibit significant signs of depressive syndrome. Moreover, caregivers have a higher risk of premature death in comparison to control subjects paired for age and gender.[14]

Ouslander et al. found that approximately 1/3 of caregivers considered UI a serious problem in patients with dementia. Such patients exhibited a greater reduction in cognitive function and greater number of behavioral alterations in comparison to the group without UI. Burden scores were higher among caregivers of incontinent patients in comparison to controls.[15]

Guarrido and Menezes[16] studied the impact on caregivers of elderly individuals with dementia under care at a psycho-geriatric service and found that the gender, age, and basic activities of daily living of the patients were not associated to caregiver burden. The authors also found that lower scores on the MMSE (worse cognitive status) were associated to greater caregiver burden.

However, a study of caregivers of patients with UI has not been previously assessed in this manner.

This is the first Brazilian study on this issue to use classic instruments that have been translated and validated for Portuguese within a rigorous international epidemiological study protocol.

The majority of patients in the sample were female and between the ages of 60 and 74 years. A total of 25.8% of the patients had UI and most had no alteration in cognitive state (Table I).

With regard to the hypotheses of the present study, there was a significant positive association between caregiver burden (Zarit score ≥ 29) and incontinent patients (ICIQ-SF ≥ 1) ($P = 0.0052$), demonstrating that UI in elderly patients produced greater caregiver burden (Table II). Likewise, the score on the MMSE was significant ($P = 0.0001$) and inversely proportional to the Zarit scale (negative association). Thus, a worse performance on the cognitive test was associated to greater caregiver burden (Table III). The mean scores on the questions of the Zarit scale were compared to the categories of continent (ICIQ-SF = 0) and incontinent (ICIQ-SF ≥ 1) patients and were significantly different in both groups on the majority of questions. The mean Zarit score was 17.8 for an ICIQ-SF score of zero (continent patient) and 22.4 for ICIQ-SF ≥ 1 (incontinent patient). The comparison of the means using the Wald test,[12] which incorporates

TABLE II. Association Between Classes of Scores on Zarit Scale and ICIQ-SF (n = 324)

| Zarit score | ICIQ-SF | | | P-value[a] |
	ICIQ-SF = 0	ICIQ-SF ≥ 1	Total	
≤28	85.9	70.1	79.2	0.0052
≥29	14.1	29.9	20.8	
Total	100.0	100.0	100.0	

[a]Rao–Scott test.

TABLE III. Association Between Classes of Scores on Zarit Scale and MMSE (n = 322)

| Zarit score | Mini-Mental State Exam (MMSE) | | | |
	Scored 24 or more	Scored 23 or less	Total	P-value[a]
≤28	88.7	67.3	79.1	
≥29	11.3	32.7	20.9	0.0001
Total	100.0	100.0	100.0	

[a]Rao–Scott test.

TABLE IV. Multivariate Logistic Regression Analysis for Presence of Caregiver Burden According to Socio-Demographic, Clinical, and Functional Characteristics of Elderly Patients in the City of Sao Paulo, Brazil, 2006

| Demographic data | Results of logistic regression | | | | |
| | | | | Confidence interval | |
	OR[a]	SD	P-value	Lower bound	Upper bound
Gender	0.81	0.24	0.49	0.44	1.47
Age (75 years or more)	1.13	0.34	0.68	0.62	2.06
Urinary Incontinence (ICIQ-SF ≥ 1)	1.96	0.58	0.022	1.10	3.51
Cognitive deficit (MMSE)	2.34	0.71	0.006	1.28	4.26
Functional state difficulties in BADL	1.32	0.58	0.39	0.69	2.49

Note: IADL was removed from the model due to problems of instability in the calculations.
[a]OR = adjusted odds ratio (95% confidence interval).

weight for complex samples, resulted in an observed F value of 5.99, with $P = 0.0163$ (Fig. 1).

The above data corroborate the results of previous studies assessing the impact of UI on the burden of spouses[3] and family caregivers.[17] Cassells and Watt[3] stress the interconnection between factors that influence caregivers, reinforcing the need for a holistic assessment of the problem beyond the focus on UI per se. However, the authors state that simple nursing intervention or minimal medical care could make a substantial difference in lessening caregiver burden and improving the quality of life of the patient. In a recent article, Gotoh et al.[17] studied the impact of UI on the psychological burden of family caregivers. A total of 757 caregivers were divided into two groups: 452 caregivers of incontinent patients (Group 1) and 305 caregivers of continent patients (Group 2). The mean total on the Zarit scale was significantly higher in Group 1 ($P < 0.001$). As in the present study, differences in the scores on the majority of the individual items were also significant, demonstrating the negative impact of UI on the psychological burden of family caregivers.
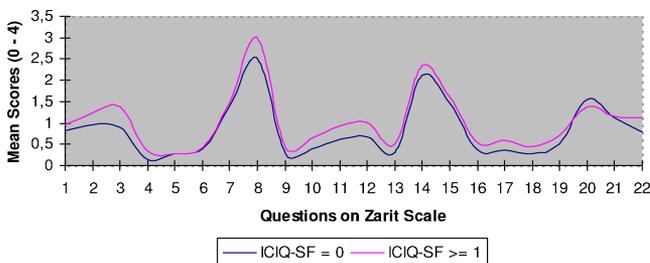

Fig. 1. Association between mean scores on each question of Zarit scale for continent (ICIQ-SF = 0) and incontinent (ICIQ-SF ≥ 1) patients (n = 324) (*P = 0.0163).*Wald test for means in complex samples.

This study has limitations that should be addressed. The entire sample was from a single city in Brazil. However, the sample was representative of the population of the city of Sao Paulo and included different urban living situations and lifestyles in the largest metropolis of South America. Another limitation was that the main source of data on caregivers was the Zarit scale. The vast majority of studies on this topic test caregiver variables such as gender, age, family relation, duration/intensity of care, emotional alterations, and associated diseases as well as other important variables. However, the main hypothesis to be tested in the present study was the association between UI of the patient and caregiver burden. It was not possible to have access to these data, which would have been of considerable value, for the presence of some of the aforementioned caregiver factors may also contribute to the increase in burden.

Although the ICIQ-SF questionnaire and Zarit scale (both translated and validated for Portuguese) are available for self-administration, the data were collected in interview form by trained professionals. Although this is not the correct procedure in studies involving these instruments, it was possible to collect data from all patients and their caregivers with a minimal rate of non-collected data. Moreover, this method of data collection has the advantage of not excluding illiterate patients or caregivers, the rate of which in this age group is high in Brazil.

The vast majority of the population of informal caregivers in Brazil has no information or necessary support regarding care for patients with UI. If formal support is not provided, there is a risk that the caregiver will end up being a patient in the system. Thus, further studies on caregivers in Brazil are needed, along with the proper training of specialized health care professionals and the implantation of orientation and support programs aimed at caregivers that involve the family, community, and state. Studies on the prevention of caregiver burden focused on a longer period of patient care at home should be carried out.

After all, those who give care cannot end up without care themselves.[16]

CONCLUSION

The present study demonstrated a significant, positive association between UI in patients and greater caregiver burden. Further studies should be carried out on this population through the SABE Study in order to better clarify the variables that influence caregiver burden.

Data from the SABE Study (Cohort A) demonstrated that UI and cognitive impairment in elderly patients were associated to an increase in caregiver burden.

REFERENCES

1. Coyne KS, Matza LS, Brewster Jordan J. We have to stop again?!: The impact of overactive bladder on family members. Neurourol Urodyn 2009;28: 969–75.
2. Tamanini JTN, Lebrão ML, Duarte YAO, et al. Analysis of the prevalence of and factors associated with urinary incontinence among elderly people in the municipality of São Paulo—SABE Study (Health, Wellbeing and Aging). Cad Saude Publica 2009;25:1756–62.
3. Cassells C, Watt E. The impact of incontinence on older spousal caregivers. J Adv Nurs 2003;42:607–16.
4. Lebrão ML, Laurenti R. Saúde, bem-estar e envelhecimento: O estudo SABE no município de São Paulo. Rev Bras Epidemiol 2005;8:127–41.
5. Silva NN. Aspectos metodológicos: Processo de amostragem. In: Lebrão ML, Duarte YAO (org). O Projeto SABE no Município de São Paulo: Uma abordagem inicial. Brasília: OPAS/OMS; 2003. p. 47–57.
6. Lebrão ML, Duarte YAO, Santos JLF, et al. Evolução das condições de vida e saúde da população idosa do município de São Paulo. São Paulo em Perspectiva, v. 22, n. 2, p. 30–45, jul./dez. 2008.
7. Abrams P, Anderson KE, Birder L, et al. Fourth International Consultation on Incontinence Recommendations of the International Scientific Committee: Evaluation and treatment of urinary incontinence, pelvic organ prolapse, and fecal incontinence—Review article. Neurourol Urodyn 2010;29:213–40.
8. Tamanini JTN, Dambros M, D'Ancona C, et al. Validation of the "International Consultation on Incontinence Questionnaire—Short Form" (ICIQ-SF) for Portuguese. Rev Saúde Pública 2004;38:438–44.
9. Scazufca M. Brazilian version of the Burden Interview scale for the assessment of the burden of care in careers of people with mental illnesses. Rev Bras Psiquiatr 2002;24:12–7.
10. Taub A, Andreoli SB, Bertolucci PH. Dementia caregiver burden: Reliability of the Brazilian version of the Zarit caregiver burden interview. Cad Saúde Pública 2004;20:372–6.
11. Almeida OP. Mini Exame do Estado Mental e o diagnóstico de Demência no Brasil. Arq Neuropsiquiatr 1998;56(3-B): 605–12.
12. Harrell FE, Jr. Overview of maximum likelihood estimation. In: Regression modeling strategies. The Wald test. New York: Springer-Verlag; 2001. p. 179–215.
13. Rao JNK, Scott AJ. On chi-squared tests for multiway contingency tables with cell proportions estimated from survey data. Ann Stat 1984;12:46–60.
14. Zarit SH. Family care and burden at the end of the life. CMAJ 2004;170: 1811.
15. Ouslander JG, Zarit SH, Orr NK, et al. Incontinence among elderly community-dwelling dementia patients. Characteristics, management and impact on caregivers. J Am Geriatr Soc 1990;38:440–5.
16. Garrido R, Menezes PR. Impact on caregivers of elderly with dementia treated at a psychogeriatric service. Rev Saúde Pública 2004;38:835–41.
17. Gotoh M, Matsukawa Y, Yoshikawa Y, et al. Impact of urinary incontinent on the psychological burden of family caregivers. Neurourol Urodyn 2009;28:492–6.