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INTEGRATIVE REVIEW ARTICLE

FACTORS ASSOCIATED WITH WORKLOAD IN FAMILY CAREGIVERS OF PERSONS WITH MENTAL DISORDER: AN INTEGRATIVE REVIEW

FATORES ASSOCIADOS À SOBRECARGA EM FAMILIARES CUIDADORES DE PESSOAS COM TRANSTORNO MENTAL: REVISÃO INTEGRATIVA

FACTORES ASOCIADOS CON LA SOBRECARGA DE TRABAJO EN FAMILIARES CUIDADORES DE LAS PERSONAS CON TRASTORNO MENTAL: UNA REVISIÓN INTEGRADORA

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ABSTRACT

Objective: identifying factors associated with family workload in studies that use FBIS scale, FBIS-BR. ***Method:*** this is a systematic review with the guiding question "what are the factors associated with family workload in studies using FBIS scale, FBIS-BR?" published from 1981 to 2013 using a controlled descriptor and two not controlled, respectively, "Family" OR "Caregiver burden" AND "Family Burden Interview Schedule". By searching the electronic databases LILACS and PubMed there were identified 65 studies and 20 selected for the review. ***Results:*** the workload was associated with some variables including sociodemographic profile, care characteristics, service characteristics, health conditions and duration of the disorder. ***Conclusion:*** studies on this topic aim to contributing in professional practice and managers of mental health, as well as qualifying care for family members in order to reducing the impact of psychosocial care. ***Descriptors:*** Family; Caregivers; Mental Health; Mental Health Services; Psychosocial Impact.

RESUMO

Objetivo: identificar os fatores associados à sobrecarga familiar em estudos que utilizam a escala FBIS, FBIS-BR. ***Método:*** trata-se de revisão sistemática com a questão norteadora "quais são os fatores associados à sobrecarga familiar em estudos que utilizam a escala FBIS, FBIS-BR?", publicados de 1981 a 2013, utilizando um descritor controlado e dois não controlados, respectivamente, "Family" OR "Caregiver burden" AND "Family Burden Interview Schedule". Através da busca nas bases de dados eletrônica LILACS e PubMed foram identificados 65 estudos e 20 selecionados para compor a revisão. ***Resultados:*** a sobrecarga esteve associada com algumas variáveis que incluem perfil sociodemográfico, características do cuidado, características do serviço, condições de saúde e duração do transtorno. ***Conclusão:*** estudos sobre esse tema visam contribuir na prática dos profissionais e gestores da saúde mental, bem como qualificar o cuidado aos familiares com o intuito de diminuir o impacto da Atenção Psicossocial. ***Descritores:*** Família; Cuidadores; Saúde Mental; Serviços de Saúde Mental; Impacto Psicossocial.

RESUMEN

Objetivo: identificar los factores asociados a la carga de trabajo familiar en los estudios que utilizan la escala FBIS, FBIS-BR. ***Método:*** se trata de una revisión sistemática con la pregunta orientadora " ¿Cuáles son los factores asociados a la carga familiar en los estudios que utilizan la escala FBIS, FBIS-BR?", publicado desde 1981 hasta 2013, utilizando un descriptor controlado y dos no controlados, respectivamente, "Family" OR "Caregiver burden" AND "Family Burden Interview Schedule" Mediante la búsqueda en las bases electrónicas de datos LILACS y PubMed se identificaron 65 estudios y 20 seleccionados para la revisión. ***Resultados:*** la carga se asoció con algunas variables incluyendo perfiles sociodemográficos, características de la atención, las características del servicio, condiciones de salud y la duración de la enfermedad. ***Conclusión:*** los estudios acerca de este tema visan contribuir en la práctica profesional y a los administradores de la salud mental, así como calificar el cuidado de los miembros de la familia con el fin de reducir el impacto de la atención psicosocial. ***Descriptores:*** Familia; Cuidadores; Salud Mental; Servicios de Salud Mental; Impacto Psicosocial.

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INTRODUCTION

In Brazil changes emerged in the mental health field from the 1980s, through the movement for psychiatric reform preceded by a social mobilization for the rights of people with psychological distress, influenced by the Italian psychiatry of Franco Basaglia. It was a time when there were discussions about madness, about the asylums as a place of segregation and social exclusion, and also a construction period of new proposals in the field of mental health by family members, professionals and users, and the emergence of the first Center of Psychosocial Care (CAPS) in São Paulo and the introduction of Psychosocial Care Centers in Santos, and in 2001 was adopted the law of Psychiatric Reform No. 10.216.[1-2]

In this context the families of people with mental disorders have an important role as caregivers and participants in the care process out from asylums; however, these responsibilities bring to the families impact and workload, which is defined as the emotional, physical and financial burden which the relatives of those with disorder are exposed to exercise their caring role.[2]

The theme of family burden needs to be further discussed and crafted by professional health services, in addition, it is important to identify the result of psychosocial care in family caregivers; therefore, the conduction of this study is justified in reason that is meant to identify the factors that are associated with the family burden brings important aspects of theoretical basis the proposed interventions to family members of people with mental disorders. In addition, the choice of scale that assesses the burden placed on family caregivers of psychiatric patients (FBIS, FBIS-BR) is justified as this is a specific scale to evaluate overload in relatives of people with mental disorder and so it is important to know what factors associated with workload through this scale.

OBJECTIVE

- Identifying the factors associated with family burden in studies using the scale FBIS, FBIS-BR.

METHODOLOGY

The systematic review with the following guiding question was carried out aimed at identifying << What are the factors associated with family burden in studies using the scale FBIS, FBIS-BR? >> Through search in electronic databases LILACS (Latin American and Caribbean Health Sciences) and PubMed (Medline Publisher).

The searches were conducted in October and November 2013, and tracked studies published from 1981 to 2013, in Brazil and abroad. The choice of descriptors was made by the descriptors in Health Sciences (DECS), and MeSH Terms descriptors.

The search in the electronic database PubMed used the descriptor MeSH Terms "Family" key words "family burden interview schedule" and "caregiver burden". The key words were used in order to include the review and the search for articles that addressed the burden on the family and the use of FBIS scale as a measurement tool overload. So we used "Family" OR "Caregiver Burden" AND "Family Burden Interview Schedule."

In the search performed in LILACS database, we used the key word family burden interview Schedule - FBIS for the same purpose described above. On this basis it was decided to not keep looking identical to held in Pubmed database, as this would result in the loss of an important study for the theme.

To select the articles inclusion and exclusion criteria were used. Inclusion criteria were: studies in humans, adults, with abstracts available, quantitative methodology in the period 1981-2013, in community mental health services, and in the following languages: Portuguese, Spanish, English and Italian. As for the exclusion criteria were studies that did not address the issue of burden placed on family and / or caregivers, who did not use the FBIS scale, FBIS-BR to asevaluate the workload, studies with other methodological approaches, such as: qualitative, reflections, reviews, etc.

The initial phase of the analysis was performed based on the titles and abstracts of all articles that met the criteria employed, or who initially did not have sufficient information to determine their exclusion. After review of the abstracts, all selected articles were obtained in full and examined according to the criteria of inclusion and exclusion established. The relevant information of the articles was recorded in instrument developed for this purpose, consisting of: authors, year of publication and location, purpose, methodology, main results / associations.

The selection and analysis of publications were conducted in pairs, with the help of the data collection instrument, and the differences found by the authors were

discussed for consensus of articles that would integrate the review. The results were summarized and presented.

The ethical aspects were seen in this study, to the extent that the information and ideas of authors who were part of the sample were respected, ensuring authorship and citation references.

RESULTS

Na figura 1 é apresentado o fluxograma que estruturou a busca e as respectivas bases de dados.

During the search process in the database 65 studies were identified for reading. An analysis of the studies was based on reading the titles and all the scanned article summaries, were initially included 56 studies in PubMed and 9 in Lilacs. After evaluating the studies were excluded duplicate articles (1), articles with a qualitative approach or with other themes (18) resulted in 46 articles for further reading.

By reading the full articles other 26 were excluded for use other measuring instruments, or be to validate these instruments studies in other countries, studies of people with dementia, elderly, and people who use alcohol and other drugs.

Whereas the criteria used and the duplicates, 20 publications that were relevant to the subject of study resulted. Items of information were recorded in the instrument drawn up for this purpose, consisting of: authors; year and place; purpose; methodology; main results/associations with workload.

Figure 1 shows the flowchart that structured the search and their databases.

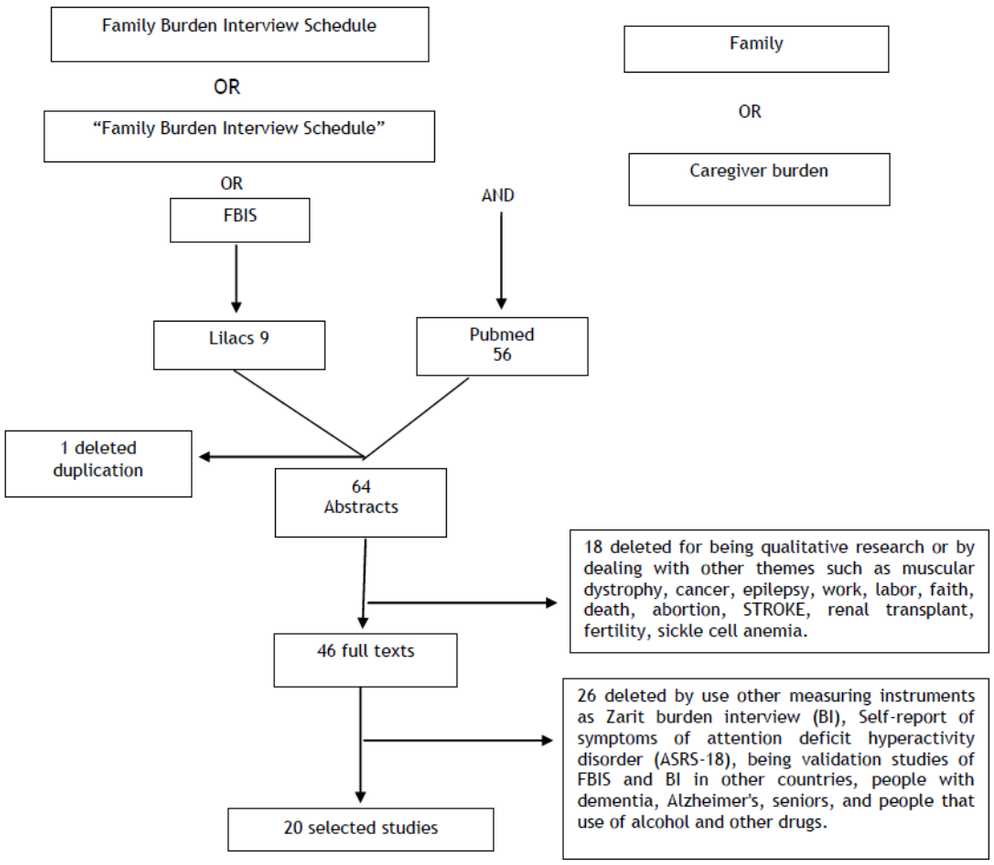

Figure 1. Flowchart of search in the databases, deleting, and selection of the studies.

DISCUSSION

The 20 selected studies used Workload Rating Scale of Family - FBIS-BR in national studies, or the scale Family Burden Interview Schedule - FBIS to measure the workload abroad.

Three versions of the Family Burden Interview Schedule were found, the first described is the Father; Kapur[3] that assesses the objective and subjective burden, composed of 24 items grouped into six areas: (1) financial burden, (2) disruption of family routine; (3) family leisure break, (4) disruption of family interaction, (5) effect on physical health; (6) effect on mental health. The total score obtained by the six areas is referred to as objective burden, as assessed by the 3-point Likert scale (0 = empty, 1 = moderate load, 2 = severe load). The total

score of objective burden (ie total score of FBIS), sum of the 24 items, ranging from 0 to 48. The subjective burden is assessed by a standard question ("How much would you say you have suffered because of disease patient? ") with response options (0 = no, 1 = a little, 2 = severely).

The Family Burden Interview Schedule (FBIS) created by Tessler; Gamache[4] was validated in Brazil, FBIS-BR is the Brazilian version, it consists of 52 items that assess the objective and subjective burden in five subscales: (A) assistance in everyday life; (B) supervision with difficult behavior; (C) financial expenses; (D) impact on daily routines; (E) concern for the patient. The objective burden is evaluated in Likert scales five points (1 = no time to 5 = every day), since the subjective burden is evaluated in Likert scales of four points to the level of discomfort to provide daily assistance and changes in life (1 = not at all to 4 = a lot) and Likert scales five points for the frequency of worries about the patients (1 = never to 5 = always or almost always).

Author	Year/Place	Objective
Lasebikan e Ayinde[5]	2013 Ibadan/ Nigeria	Determine the effects of level of psychopathology and adherence to medication, and burden of caregivers in schizophrenia.
Khoshknab et al[6]	2013 Tehran/ capital of Iran	Evaluate the impact of the intervention group psycho-educational on family caregivers to overload Iranian patients with schizophrenia.
Kate et al[7]	2013 India	Study positive aspects of care and its related in caregivers of patients with schizophrenia.
Grover et al[8]	2013 India	Compare evaluated by medical and overload by the caretaker of patients with schizophrenia and Bipolar disorder
Lasebikan e AYINDE[9]	2013 Ibadan/ Nigeria	To determine the prevalence and sociodemographic correlates of caregiver overload in schizophrenia.
Kate et al[10]	2013 India	Study the quality of life in caregivers of patients with schizophrenia, and the relationship between quality of life, coping and overload.
Siu et al[11]	2012 China/ Hong Kong	Assess the determinants of overhead reported by caregivers of adults with OCD.
Shibre et al [12]	2012 Ethiopia Butajira	Evaluate overload of the caregiver and the predictors of the load in a rural community.
Camilo et al[13]	2012 Brazil	Evaluate the quality of mental health services from the perspective of patients, family members and professionals.
Grover e Dutt[14]	2011 India	Analyze correlations between perceived overload and quality of life of caregivers of patients with OCD.
Vikas et al[15]	2011 India	Assess the psychosocial impact of OCD patients and their caregivers.
Neto et al[16]	2011 Brazil	Assessing degrees of objective and subjective, overload, of relatives of OCD individuals in public and private network samples.
Albuquerque et al[17]	2010 Brazil	Investigate the objective and subjective overload in three different types of caregivers.
Barroso et al[18]	2009 Brazil	Identify the relative importance of predictors of subjective overload.
Wong et al[19]	2008 EUA/ New York	Examine the degree of overload in families of patients during the period 1 and the onset of psychosis.
Bandeira et al[20]	2008 Brazil	Assessing the validity of the Brazilian version of the scale Family Burden Interview Schedule (FBIS-BR).
Chien et al[21]	2007 China/ Hong Kong	Analyze the overhead in Chinese Families and test associations with demographic characteristics, social and family factors and health condition.
Barroso et al[22]	2007 Brazil	Describe the objective and subjective overload of a sample of family.
Bandeira et al[23]	2007 Brazil	Evaluate the reliability of the Brazilian version of the scale Family Burden Interview Schedule.
Bandeira et al[24]	2005 Brazil	Make the cross-cultural adaptation to the Brazil of the scale Family Burden interview Schedule (FBIS)

Figure 2. Quantitative studies of mental health overload according to authors, year of publication, place and purpose of the studies. 1981-2013 periods.

An updated version of the FBIS scale was developed later[25], called FEIS (Family Experiences Interview Schedule) and has 180 items, which included the measurement of positive aspects of the provision of care. However, it can be seen that the FEIS has not been widely used, being found in only one study evaluating the workload to family members.[19]

Regarding the language, most of the items 65% is in English. Regarding the year, more than 50% of the publications are concentrated in 2011-2013.

The articles that make up the review are all category "original", and the methodological quality of these studies, they focus on levels of evidence 3 and 4, in which two[6,12] are level 3, and eighteen [5,7-11,13-24] level 4.

A scale used in the studies was the Global Assessment of Functioning (GAF) used to measure psychological well-being, which was applied in 4 studies, together with other instruments.[5,7-8,11]

In one study the FBIS was used with a large number of different scales, which were the Positive and Negative Syndrome Scale (PANSS), Scale for Positive Aspects of Caregiving Experience (SPACE) Involvement Evaluation Questionnaire (IEQ), Global Assessment of Functioning (GAF), Social Support Questionnaire (SSQ) and the General Health Questionnaire (GHQ-12).[7]

The scales that were found in only one study are: Scale for Positive Aspects of Caregiving Experience (SPACE),[7] evaluation scale of Professional Satisfaction in Mental Health Services (SATIS-BR),[13] Labor Impact Assessment Scale Mental Health Services (IMPACT-BR) ,[13] Depression Rating Scale (HDRS), [15] Mini International Neuropsychiatric Interview (MINI),[16] Burden Interview (BI) ,[20] Scale Self Reporting Questionnaire (SRQ-20) ,[20] Family Assessment Device (FAD) ,[21] Social Support Questionnaire (SSQ6) ,[21] MOS 36 -Item Short Form Health Survey.[21] Also found in 2 studies the scale Involvement Evaluation Questionnaire (IEQ),[7-8] and 3 study the scale World Health Organization Quality of Life BREF (WHOQOL-BREF)..[10,14-5]

Author	Methodology	Main Results/ Associations
Lasebikan e Ayinde[5]	368 caregivers, 368 patients. Instrument: FBIS, GHQ-12, GAF, PANSS.	FBIS scores were positively associated with the PANSS scores, but negatively with GAF.
Khoshknab et al[6]	71 caregivers Instrument: FBIS Father; Kapur (1981).	After intervention by the score of the FBIS was smaller in the case group compared to the control group.
Kate et al[7]	100 caregivers, 100 patients. Instrument: FBIS, PANSS, SPACE, IEQ, SSQ, GAF, GHQ-12.	SPACE; Workload associated with negatively with PAC.
Grover et al[8]	122 caregivers, 122 patients. Instrument: FBIS, Hindi-IEQ, GAF.	Family income; caregiver education; n° of hours in care; Caregiver work; GAF Scores.
Lasebikan e AYINDE[9]	368 caregivers, 368 patients Instrument: FBIS Father; Kapur, GHQ-12.	Age, education, occupation, relationship with patient, disease duration, and hours spent with patients.
Kate et al[10]	100 caregivers, 100 patients. Instrument: FBIS, WHOQOL-BREF.	Global Objective workload 1.3 (0.5) Total score goal 13.62 (7.63) Subjective Workload 1.5 (0.5)
Siu et al[11]	77 caregivers, 77 patients. Instrument: FBIS of Father; Kapur, GAF.	Objective Workload: scores of GAF, monthly household income. Subjective Overload: scores of GAF, sex of caregiver.
Shibre et al [12]	307 caregivers Instrument: FBIS of Father; Kapur.	Monitoring of medication; positive symptoms; diagnosis of schizophrenia.
Camilo et al[13]	35 family members, 35 patients, 8 professionals Instrument: SATIS-BR, IMPACTO-B, FBIS-BR.	Global workload Objective: 1,91 Subjective: 2,58
Grover e Dutt[14]	50 caregivers, 50 patients. Instrument: FBIS of Father; Kapur, WHOQOL-BREF.	Objective Workload: leisure break and interaction, greater financial burden, physical health. Subjective Workload: quality of life. Scores of WHOQOL-BREF
Vikas et al[15]	62 caregivers, 62 patients. Instrument: FBIS of Father; Kapur, WHOQOL-BREF, HDRS.	Female; occupation; marital status; schooling; income; housing (rural); duration of treatment; hospitalization; HDRS.
Neto et al[16]	30 family members, 30 patients. Instrument: (MINI), FBIS-BR.	Significance in objective dimension: sample of the public network; Significance in subjective dimension in the sample private clinic.
Albuquerque et al[17]	90 family members, 30 parents, 30 siblings, 30 spouses. Instrument: FBIS-BR.	The groups did not differ with respect to levels of objective and subjective global overload.
Barroso et al[18]	150 family members Instrument: FBIS-BR	Income; own children; work; coping; leisure; religion; satisfaction with care; disorder information.
Wong et al[19]	23 family members Instrument: FEIS.	Global Objective: 1 18.2, recent 19.2. Subjective: 1 2.7, rec. 2.5.
Bandeira et al[20]	100 family members. Instrument: FBIS-BR, BI, SRQ-20.	FBIS-BR significant correlations with the scale BI and with SRQ - 20 ($p < 0,01$).
Chien et al[21]	203 family caregivers. Instrument: FBIS of Father; Kapur, FAD, SSQ6, MOS 36.	Income; Number of family members (single caregiver); SSQ6; MOS 36-Item Short Form Health Survey
Barroso et al[22]	150 family members Instruments: FBIS-BR.	Objective: subscale A (71,4%) Subjective: subscale E (79,4%).
Bandeira et al[23]	243 family members Instrument: FBIS-BR	Cronbach's alpha varied 0.58 to 0.90. Pearson ranged 0.54 to 0.92.
Bandeira et al[24]	20 family members Instrument: FBIS of Father; Kapur, FBIS-BR.	Modifications on issues in 4 categories: replacement of terms, inclusion of words or situations and inclusion of items in range.

Figure 3. Quantitative studies of mental health overload according to authors, methodology, main results/associations with the overload. 1981-2013 periods.

The studies found mostly showed reduced samples. Selected papers presented samples ranging from 20 participants, smaller sample, the 368 participants, larger sample, and most of the articles (12) concentrated samples ranging from 20 to 100 participants.[7,10-1,13-7,19-20,24]

Regarding the averages and standard deviation, the total score of FBIS ranged from 9,10 (7,17) to 40,51 (3,17) on a scale of 0 to 48.[6,11] Objective global burden showed a mean and standard deviation ranging from 1,06 (0,8) 1,59 (0,66) on a scale of 0 to overload subjective 2.[8,15] have the mean and standard deviation ranged from 1,00 (0,8) to 1,5 (0,5) in a range from 0 to 2. [7-8,10]

In relation to average and standard deviation of the FBIS-BR average of objective burden ranged from 1,25 to 3,14 (0,72) on a scale of 1 to 5.[16-7] Already subjective burden the mean and standard deviation ranged from 1,55 (0,73) to 3,16 (0,66) on a scale from 1 to 5.[13]

A study that investigated overload in three different types of caregivers, parents, siblings and spouses, found that the groups did not differ with respect to the degree of objective and subjective global burden. Indicating that the caring role affected the three similarly groups, however, when evaluated on specific issues were no differences between groups.[17] The higher prevalence of burden was 98,7% and the lowest prevalence of overhead between studies was 34,4%.[7,11]

Regarding factors associated with overload associations were found with some variables including sociodemographic, care characteristics, service characteristics, health conditions and duration of the disorder. In two studies the burden was associated with age and number of hours per day in care.[8-9]

Schooling was associated workload in three studies. [8-9,15] Overloading the family was associated to the education of people with disorder,[6] it was also associated with low education of the caregiver;[9,15] been identified association between female and workload in two studies.[11,15] Family income was associated workload in five studies.[8,11,15,18,21] Since three of these studies workload was associated with low family income.

The fact that the caregiver have paid work was associated with overload in four studies.[8-9,15,18] There was also an association between duration of disease and treatment with the overhead in two studies.[9,15]

In two studies the burden was associated with health conditions and the interruption of leisure.[14,18] The variables marital status, having children, receive information about the disorder and be the only caregiver was associated with a study, respectively.[15,18,21]

In a randomized controlled study, at baseline the FBIS score was not significantly different between cases and controls. After the intervention, the mean total score of the FBIS was significantly lower in the case group compared with the control group (P < 0,001).[6] Scores of FBIS were associated with the PANSS scores in one study,[5] but negatively with GAF in two studies.[5,8] In the present study, methodological limitations of articles difficult comparison. This issue was also highlighted in another study of systematic review.[26]

CONCLUSION

It was evident that some sociodemographic variables, health conditions, compared with the health service and related to the family context interfere in family burden. The development of studies on this topic aims to contribute in professional practice and managers of mental health, as well as qualify the care of family members in order to reduce the impact of psychosocial care.

There are several studies that address the issue burden; however, are outnumbered those who deal with the associated factors. Thus, it is expected that further studies can be carried out, contributing to the spread of actions on the issue of overload.

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