Journal of Nursing
Revista de Enfermagem
UFPE On Line
ISSN: 1981-8963

INTEGRATIVE REVIEW ARTICLE

SOCIAL SUPPORT NETWORK TO THE CAREGIVING FAMILY OF AN INDIVIDUAL WITH A CHRONIC DISEASE: INTEGRATIVE REVIEW

REDE DE APOIO SOCIAL À FAMÍLIA CUIDADORA DE INDIVÍDUO COM DOENÇA CRÔNICA: REVISÃO INTEGRATIVA

RED DE APOYO SOCIAL A LA FAMILIA CUIDADORA DE INDIVIDUO CON ENFERMEDAD CRÓNICA: REVISIÓN INTEGRADORA

Bruna Sodré Simon[1], Maria de Lourdes Denardin Budó[2], Raquel Pötter Garcia[3], Tais Falcão Gomes[4], Stefanie Griebeler Oliveira[5], Marciele Moreira da Silva[6]

ABSTRACT

Objective: to evaluate in the literature the influence of the support network to families on the caring process for a relative with a chronic disease. ***Method:*** integrative review, with collection in June 2012, in the bases Latin American and Caribbean Health Sciences Literature (LILACS) and Medical Literature Analysis and Retrieval System Online (MEDLINE), with the descriptors "social support" and "chronic disease"; the words "family", "family caregivers", "caregivers"; and the Spanish, English, or Portuguese languages. The data were worked out through evidence analysis. ***Results:*** for the family members, social support is important in the illness process of one of its members, contributing to the family's adjustment to the new routine, the decreased overburden of care, the maintenance of domestic activities, and the financial management. ***Conclusion:*** it's regarded as needed that the health professionals realize the importance of the other components of the support network, so that, together, they can strengthen actions in favor of the well-being of everyone involved. ***Descriptors:*** Social Support; Chronic Disease; Family Health; Nursing Care; Nursing.

RESUMO

Objetivo: avaliar na literatura a influência da rede de apoio às famílias no processo de cuidar de um familiar com doença crônica. ***Método:*** revisão integrativa, com coleta em junho de 2012, nas bases Literatura Latino-Americana e do Caribe em Ciências da Saúde (Lilacs) e Medical Literature Analysis and Retrieval System Online (MedLine), com os descritores "apoio social" e "doença crônica"; as palavras "família", "familiares cuidadores", "cuidadores"; e os idiomas espanhol, inglês ou português. Os dados foram trabalhados com análise de evidências. ***Resultados:*** para os familiares, o suporte social é importante no adoecimento de um de seus membros, contribuindo na adaptação da família à nova rotina, na diminuição da sobrecarga do cuidado, na manutenção das atividades domésticas e na gestão financeira. ***Conclusão:*** mostra-se necessário que os profissionais da saúde percebam a importância dos demais componentes da rede de apoio, para que, juntos, possam fortalecer ações em prol do bem-estar dos envolvidos. ***Descritores:*** Apoio Social; Doença Crônica; Saúde da Família; Cuidados de Enfermagem; Enfermagem.

RESUMEN

Objetivo: evaluar en la literatura la influencia de la red de apoyo de las familias en el proceso de cuidar de un familiar con enfermedad crónica. ***Método:*** revisión integradora, con recogida en junio de 2012, en las bases Literatura Latino-Americana y del Caribe en Ciencias de la Salud (Lilacs) y Medical Literature Analysis and Retrieval System Online (MedLine), con los descriptores "apoyo social" y "enfermedad crónica"; las palabras "familia", "familiares cuidadores", "cuidadores"; y los idiomas español, inglés o portugués. Los datos fueron trabajados con análisis de evidencias. ***Resultados:*** para los familiares, el soporte social es importante en la enfermedad de uno de sus miembros, contribuyendo a la adaptación de la familia a la nueva rutina, la disminución de la sobrecarga de la atención, el mantenimiento de las actividades domésticas y la gestión financiera. ***Conclusión:*** se muestra necesario que los profesionales de la salud perciban la importancia de los demás componentes de la red de apoyo, para que, juntos, puedan fortalecer acciones en favor del bienestar de los involucrados. ***Descriptores:*** Apoyo Social; Enfermedad Crónica; Salud de la Familia; Cuidados de Enfermería; Enfermería.

[1]Nurse. MS Nursing student at the Graduate Nursing Program of Universidade Federal de Santa Maria (PPGEnf/UFSM). REUNI scholarship holder. Member of the research group Care, Health, and Nursing, of UFSM. Cacequi (RS), Brazil. Email: bru.simon@hotmail.com; [2]Nurse. PhD in Nursing. Associate Professor at the Nursing Department of PPGEnf of UFSM. Subchief of the research group Care, Health, and Nursing, of UFSM. Email: lourdesdenardim@gmail.com; [3]Nurse. MS Nursing student at the PPGEnf/UFSM. REUNI scholarship holder. Member of the research group Care, Health, and Nursing, of UFSM. Email: raquelpotter_@hotmail.com; [4]Undergraduate student from the 6th semester of the Nursing course of UFSM. FIPE/UFSM scholarship holder. Member of the research group Care, Health, and Nursing, of UFSM. Email: taissfg@gmail.com; [5]PhD Nursing student at the Universidade Federal do Rio Grande do Sul (UFRGS). Assistant Professor I at the School of Nursing of the Universidade Federal de Pelotas (UFPel). Member of the research group Care, Health, and Nursing, of UFSM, and the Group for Cultural Studies in Health Education and Nursing, of UFRGS. Email: stefaniegriebeler@yahoo.com.br; [6]Nurse. MS in Nursing at the PPGEnf/UFSM. Specialist in Collective Health. Professor at the Universidade Regional Integrada do Alto Uruguai e das Missoes (URI). Member of the research group Care, Health, and Nursing, of UFSM. Email: enfmarciele@yahoo.com.br

INTRODUCTION

The Brazilian epidemiological scenario changes since the 1980s, as, prior to this period, the predominant causes of morbidity and mortality were due to infectious diseases. However, in the face of urbanization, access to health services, technological advances, cultural changes, increased life expectancy, and demographic transformation, chronic diseases have become a public health problem.[1]

The chronic non-communicable diseases (CNCDs), besides affecting the individual for a long period, require continuous actions and procedures from the health services. Among the main CNCDs stand out hypertension, diabetes mellitus, neoplasias, cerebrovascular diseases, and chronic obstructive pulmonary diseases.[1]

Chronic illness provides several limitations, changes the routine, generates financial costs, and demand continued care. These aspects affect both the individual with the disease and her/his family.[2-4] Family is a dynamic unit which may be constituted by persons with consanguineous, interest, and affection ties.[5] Depending on the situation and the time of disease onset, the family adopts different coping ways, but "care and protection for its members" is its main function.[6]

In order to assist in the care and someone's coexistence with chronic illnesses, the family often seeks support in its social networks. Social networks, when stable, active, and reliable, generate health, because they have a helping condition, speed the rehabilitation and healing process, and increase survival.[7] One understands as social network all relationships that people perceive as important, i.e. their interpersonal niche.[7]

Given these considerations, it's needed that health professionals recognize the social support networks to families, so that they're also incorporated into their care practices. This way, the guiding question of this study was << ***What is the influence of the support network to the family in the caring process for the individual with a chronic disease?*** >>. To answer to this question, one aimed at evaluating, in the literature, the influence of the support network to families on the caring process for a relative with chronic disease.

METHOD

It's an integrative review analyzing relevant researches which provides a knowledge synthesis and points out gaps that must be studied in order to contemplate and fill these spaces.[8] For carrying out this kind of research, six steps were taken:

a) Identification of the theme or research question;
b) Establishment of inclusion and exclusion criteria;
c) Selection of elements which will be extracted from the selected studies;
d) Categorization of studies;
e) Evaluation of the included findings;
f) Interpretation of results and, ultimately, presentation of the knowledge synthesis.[9]

Data collection was conducted in June 2012, in the Virtual Health Library (VHL), in the databases Latin American and Caribbean Health Sciences (LILACS) and Medical Literature Analysis and Retrieval System Online (MEDLINE). One used as search strategy in LILACS ("APOIO SOCIAL") AND "doenca cronica" [Subject descriptor] and (("FAMILIA") or "FAMILIARES-CUIDADORES") or "CUIDADORES" [Words] and "ESPANHOL" or "INGLES" or "INGLES" [Language]; and in MEDLINE ("apoio social") AND "doenca cronica" [Subject descriptor] and (("FAMILY") or "CAREGIVERS--FAMILY") or "CAREGIVERS" [Words] and "ESPANHOL" or "INGLES" or "PORTUGUES" [Language].

For collecting data, one used a box covering the following items: number of the paper in the database, reference, publication year, location, authors' professional training, and language.

One found 27 papers in accordance with the inclusion criteria: abstract freely available online, research papers which fit the theme addressed. Afterwards, they were classified into evidence levels, and most of them showed to be level 6.

It's worth indicating that the choice of including studies with evidence level 6 was a consequence of reading 27 preselected papers covering different evidence levels, when one found out that the evidence level 6 had a prevalence of 79%; 9% had an evidence strength 4 and 12% had an evidence strength 2. Thus, one opted to conduct the analysis and discussion only of papers with evidence level 6, i.e. those from a single descriptive or qualitative study.[10] In turn, as exclusion criteria, one elected: papers without abstract in the database or those incomplete (Figure 1).

The analysis of extracted data was conducted on a descriptive way, allowing the nurse to evaluate evidences. In nursing care, recognizing the evidence levels helps putting them into practice during care, in order to

provide a better possibility of solving problems.[10] It's noteworthy that the levels were separately evaluated by two people, and whenever there was disagreement, a third person classified them.

For assisting in data analysis, one used an adaptation of the instrument[11] which contains: paper identification, methodological characteristics, assessment of methodological rigor, interventions under study, main findings, and considerations.

LILACS	MEDLINE
	Total findings
7	516
	Weren't papers
1	08
	Without abstract or incomplete
0	79
	Literature review
0	73
	Weren't in accordance with the theme
4	286
	Weren't fully available online
0	45
	Hadn't evidence level 6
0	8
	Total of selected papers
2	17

Figure 1. Structure of exclusions from this study. LILACS and MEDLINE, 2012.

RESULTS

In this study, 19 studies were analyzed[12-30], which met the inclusion criteria previously listed. In order to better detailing these studies, their features are generally presented below.

Starting from the analysis of the publication year of papers, one sees that most of them were from 2007 to 2009 and 2011 (Figure 2).

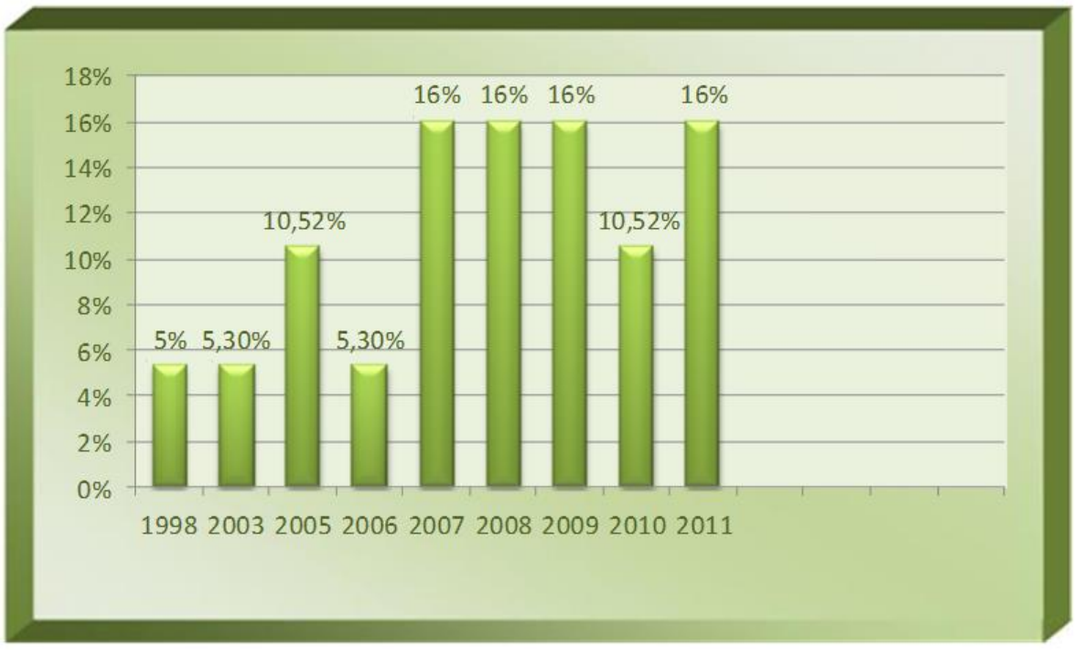

Figure 2. Distribution of studies according to the publication year. LILACS and MEDLINE, 2012.

Among the papers, the language standing out was English, with 89.48% of publications, followed by Portuguese and Spanish, with 5.26% each. This finding may be related to the greater number of studies found in the database MEDLINE, which has in its platform a high index of publications in that language.

Regarding the location from where the studies come from, 21% were from the United Kingdom; Finland, China, Australia, and the United States, had, each, 16% of publications; and 5.3% were from Brazil, Colombia and Japan.

Concerning the profession of the authors of papers under analysis, 53% were nurses; 21% were physicians; 16% were psychologists; 5% were communication specialists; and 5% of papers were written by a multiprofessional team.

Family members indicate that the social support is beneficial[12], it helps providing information on how to deal with illness, adapting the family[12-14], and decreasing the overburden of care.[13,15,16]

The social networks which offer an informal support are the family, the school, and the support groups; in turn, a formal support is

provided by health professionals.[13,14,17,18] The relatives and closest friends show to be good supporters when the difficulties emerge[19], and this support may be both physical and psychological.[20] The main source of support reported is the family[21], and in one study the spouse was reported as "protection spouse".[22] This support received by the family is positive, since it helps strengthening the family union.[23]

The support provided by family members is related to the maintenance of daily life, financial management[24], and household chores or activities in the community.[22,24] Children were highlighted as a source of support, as they help with regard to transportation to appointments and grocery shopping.[21]

The formal support was revealed in studies as significant for the caring process for a relative with a chronic disease.[13,16,20,24,25] This kind of support helps reducing the overburden of care on the part of the caregiver[16]; it may be provided by a multidisciplinary team, which enables physical health support and training for home care.[24]

Regarding the support of health professionals, this is characterized by hearing moments.[20,26] One study shows the importance of nurse's presence when it's asked[26], as well as counseling to help families to cope with the relative at home.[26,27] Also, the professionals are seen as a source of information[21] on the disease and its meaning.[28]

A study carried out with parents of children with chronic health conditions shows that when parents received support from health professionals they had less conflict in the family, less sadness and fear, a better acceptance of the situation, and closer social relationships.[25]

Besides, as a source of formal support, one highlights the financial resources from government initiatives, along with the materials received from health services, which assist families in caring and meeting their needs.[13,19]

As for houses and support groups, the family members revealed that attending these places contributes to exchange experiences related to illness and care.[13,17-19,29] This exchange of experiences is reported as an act of concern and compassion for other families, since it allows them to avoid or overcome the difficulties they would face[19], characterized as emotional support.[22]

The nursing homes, places where the family members wait for the hospitalization period or treatment, are essential for continuity of care, supervision of adequate care, and rest for the family.[23] Also, the involvement with support groups or through the internet is critical to the acquisition of knowledge on the diagnosis of disease.[14,18]

However, among the results one found out that, in some cases, the family doesn't receive support, something which makes it more difficult to cope with the disease, to reorganize the family, and it causes an overburden of care.[23,30] The difficulty faced by the family has a significant correlation with the amount of support provided by its members[20,24], and when there's a lack of this support, a number of conflicts may occur.[25]

An inadequate assistance received from the professionals and service providers was highlighted by family members as an abandonment feeling.[19] Inadequate follow-up after diagnosis and poor communication between professionals and health services leads to a support deficit.[19] Moreover, the lack of professionals[19] and turnover in the health teams[20,27] prevent families from receiving the needed support.

It's noteworthy that the support received is varied[18-21], because the family's experience with social networks faces oscillating support moments, given the uncertainty through which the network interprets the sick individual's limitations.[18,21] Often, over time, the support received undergoes a decrease.[19,20]

DISCUSSION

In the face of the papers under analysis, one noticed that the support received from social networks is beneficial for the families which have an individual with a chronic disease. Several studies bring this evidence among its results[31-34], characterizing the relevance of addressing this theme in the development of researches to favor the caring practices.

One found out two kinds of support: informal and formal. The informal support is characterized as that provided by relatives and friends, neighbors, religious congregations, and community groups. In turn, the formal support is that offered by professionals and health services.[31-33,35] There're studies highlighting these networks as the most mentioned by subjects.[31-34]

When receiving the support, families have a decrease in the overburden, both related to the care provided to the relative and to the process of adapting the everyday activities directed towards the disease. These activities range from help related to hygiene, feeding, and transport to financial matters.[31,32]

The aid in performing these activities becomes appropriate, since the family, in the face of chronic illness, needs to undergo a reorganization.[36] Sometimes, the family/caregiver's overburden is caused by the lack of support received from the social network concerned.[35]

Added to this, the support received from health professionals was also found in the studies. This kind of support allows the family to obtain guidance regarding home care. A study carried out with family caregivers at home reveals that the families seek support from professionals, especially nurses, in the face of difficulties arising from home care.[37] Yet, another research carried out with caregivers of patients undergoing home care states that, given the need to care for, the family members require continued learning, something which is offered by the health professionals.[36]

Families report that when they receive support from the services and health professionals there's a decrease in the sadness of having a beloved one with a chronic disease, easing the uncertainty related to the way how the caring procedures will be undertaken and reducing their overburden. Thus, the professionals are often asked to attend home in order to perform more specific caring procedures, provide guidance, and conduct periodic evaluations of the ill relative.[37]

Another relevant kind of support is the financial one, since, as it's known, due to the chronic disease, the family has expenses with treatment and, sometimes, some relative needs to stop performing her/his labor activities, which, consequently, causes a decrease in the family's financial budget. Studies reveal that a financial support is offered to families by the health services, support groups, and the family itself.[31]

On the other hand, there're cases where no formal support is available, especially in the health services, which present a turnover of professionals, and one notices that this complicates the bond between family/professionals/individuals. A research carried out in Paraná reveals that family members stressed they don't receive a support from health professionals, thus hindering coping with home care and the understanding on the disease.[31]

Even with the evidence that social networks are beneficial and available, providing both informal and formal support, it's worth highlighting that such a support isn't always offered on an ongoing basis. Thus, as the chronically ill individuals suffer with the nuances of their disease, the support also changes according to the situations faced by the family and individuals. This way, when one has a long-term illness, the social networks have an interference with its quality and its quantity.[7]

Still from this perspective, the participation in support groups is very important, indeed, because at these moments families take the opportunity to exchange experiences with regard to the caring procedures and information on the diseases. During the meetings in support groups, the activities allow relatives to feel embraced, appreciated, and soften their overburden of care.[33]

CONCLUSION

Evidence from the selected studies reveals, positively, the action of social networks to assist families in caring for the relative with a chronic disease. But there's also evidence that the lack of support becomes negative, so that care constitute an overload. The support networks are mainly formed by family, friends, religious congregations, and support groups. The support from health professionals is also highlighted in this context.

This way, it shows to be necessary that health professionals, besides providing support to families during the chronic illness process, realize the importance of the other components of the support network, so that, together, they can strengthen their actions to favor the well-being of families and individuals.

Additionally, nursing, a profession which has the legitimation of care as its main feature, is relevant in this process of recognizing/knowing the networks. Nurses need to develop their caring procedures by establishing partnerships with the other components of the support network to families, in order to allow the exchange of experiences and provide proper care with regard to the particularities of each family experiencing the health/illness process.

In this review, one noticed that there're few published studies on the social networks involving families, something which may be characterized as a gap and it emphasizes the need for developing researches related to this theme. Furthermore, the researches already published mostly involve the families of children, pointing out the need for studies involving the families of adults.

REFERENCES

1. Ministério da Saúde (Brasil). A vigilância, o controle e a prevenção das doenças crônicas não-transmissíveis: DCNT no contexto do Sistema Único de Saúde Brasileiro. Brasília: Organização Pan-Americana da Saúde; 2005.

2. Tamanini G, Fermandes GCM, Melo A. A vivência da família no cuidado ao portador da Doença de Alzheimer em uma área rural. In: Elsen I, Souza AIJ, Marcon SS. Enfermagem à família: dimensões e perspectivas. Maringá: UEM; 2011. p. 147-56.

3. Violim MR, Bringmann PB, Marcon SS, Waidman MAP, Sale CA. O significado de conviver com um familiar com estomia por câncer gastrointestinal. Rev Rene [Internet]. 2011 July/Sept [cited 2012 NOV 23];12(3):510-17. Available from: http://www.revistarene.ufc.br/revista/index.php/revista/article/view/256/pdf

4. Motta MGC, Issi HB, Milbrath VM, Ribeiro NRR, Resta DG. Famílias de crianças e adolescentes no mundo do hospital: ações de cuidado. In: Elsen I, Souza AIJ, Marcon SS. Enfermagem à família: Dimensões e perspectivas. Maringá: Eduem; 2011.

5. Elsen I, Althoff CR, Manfrini GC. Saúde da família: desafios teóricos. Fam Saúde Desenv [Internet]. 2001 July/Dec [cited 2012 June 27]; 3(2):89-97. Available from: http://ojs.c3sl.ufpr.br/ojs2/index.php/refased/article/view/5048/3817

6. Guimarães TMR, Miranda WL, Tavares MF. O cotidiano das famílias de crianças e adolescentes portadores de anemia falciforme. Rev Bras Hematol Hemoter [Internet]. 2009 [cited 2012 June 27]; 31(1):9-14. Available from: http://www.scielo.br/pdf/rbhh/v31n1/aop0209.pdf

7. Sluzki CE. A rede social na prática sistêmica. 2th ed. São Paulo: Casa do Psicólogo; 2003.

8. Mendes KDSM, Silveira RCCP, Galvão CM. Revisão Integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. Texto Contexto Enferm [Internet]. 2008 Oct/Dec [cited 2012 June 27];17(4):758-64. Available from: http://www.scielo.br/pdf/tce/v17n4/18.pdf

9. Pompeo DA, Rossi LA, Galvão CM. Revisão integrativa: etapa inicial do processo de validação de diagnóstico de enfermagem*. Acta Paul Enferm [Internet]. 2009 [cited 2012 June 27];22(4)434-38. Available from: http://www.scielo.br/pdf/ape/v22n4/a14v22n4.pdf

10. Galvão CM. Níveis de evidência. Acta Paul Enferm [Internet]. 2006 [cited 2012 June 27]; 19(2):v. Available from: http://www.scielo.br/pdf/ape/v19n2/a01v19n2.pdf

11. Ursi ES, Galvão CM. Prevenção de lesões de pele no perioperatório: revisão integrativa da literatura. Rev Latino-am Enfermagem [Internet]. 2006 Jan/Feb [cited 2012 Oct 05]; 14(1):124-31. Available from: http://www.scielo.br/pdf/rlae/v14n1/v14n1a17.pdf

12. Ortiz LB, González GMC, Díaz LC, Afanador NP, Herrera BS. Soporte social con el uso de TIC's para cuidadores familiares de personas com enfermedad crônica. Rev salud pública [Internet]. 2011 May/June [cited 2012 Aug 20]; 13(3):446-57. Available from: http://www.scielo.org.co/pdf/rsap/v13n3/v13n3a07.pdf

13. Nóbrega VM, Collet N, Silva KL, Coutinho SED. Rede e apoio social das famílias de crianças em condição crônica. Rev Eletr Enf [Internet]. 2010 Sept [cited 2012 Aug 2];12(3):431-40. Available from: http://www.fen.ufg.br/revista/v12/n3/v12n3a03.htm

14. Read J, Kinali M, Muntoni F, Weaver T, Garralda ME. Siblings of young people with duchenne muscular dystrophy e a qualitative study of impact and coping. Eur J Paediatric Neurol [Internet]. 2011 Jan [cited 2012 Aug 2];15(1):21-8. Available from: http://www.ejpn-journal.com/article/S1090-3798(10)00142-X/fulltext

15. Yey LL, Liu SK, Hwu HG. Needs and demands for community psychiatric rehabilitation programs from the perspectives of patients and caregivers. Community Ment Health J [Internet]. 2010 July [cited 2012 Aug 2];47(4):415-23. Available from: http://link.springer.com/article/10.1007/s10597-010-9336-y#page-1

16. Chiou JC, Chang HY, Chen IP, Wang HH. Social support and caregiving circumstances as predictors of caregiver burden in Taiwan. Archives of Gerontology and Geriatrics [Internet]. 2009 May [cited 2012 Aug 09];48(3):419-24. Available from: http://www.aggjournal.com/article/S0167-4943(08)00080-0/pdf

17. Ganonni AF, Shute RH. Parental and child perspectives on adaptation to childhood chronic illness: a qualitative study. Clin Child Psychol Psychiatry [Internet]. 2009 Jan [cited 2012 Aug 09]; 15(1):39-53. Available from:

http://ccp.sagepub.com/content/15/1/39.full.pdf+html

18. Kicken ED, Bute JJ. Uncertainty of social network members in the case of communication-debilitating illness or injury. Qual Health Res [Internet]. 2008 Jan [cited 2012 Aug 09]; 18(1):5-18. Available from: http://qhr.sagepub.com/content/18/1/5.full.pdf+html

19. Ware J, Raval H. A qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and in retrospect. Clin Child Psychol Psychiatry [Internet]. 2007 Oct [cited 2012 Aug 09];12(4):549–65. Available from: http://ccp.sagepub.com/content/12/4/549.full.pdf+html

20. Brewer HM, Smith JA, Eatough V, Stanley CA, Glendinning NW, Quarrell OWJ. Caring for a child with juvenile huntington's disease: helpful and unhelpful support. J Child Health Care [Internet]. 2007 Mar [cited 2012 Aug 09];11(1):40–52. Available from: http://chc.sagepub.com/content/11/1/40.full.pdf+html

21. Merrel J, Kinsella F, Murphy F, Philpin S, Ali A. Support needs of carers of dependent adults from a Bangladeshi community. J Adv Nurs [Internet]. 2005 Sept [cited 2012 Aug 09]; 51(6):549–57. Available from: http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.2005.03539.x/pdf

22. Richardson JC, Ong BN, Sim J. Experiencing chronic widespread pain in a family context: giving and receiving practical and emotional support. Sociol Health Illn [Internet]. 2007 Apr [cited 2012 Aug 09]; 29(3):347-65. Available from: http://onlinelibrary.wiley.com/doi.10.1111/j.1467-9566.x/pdf

23. Wang KWK, Barnard A. Caregivers' experiences at home with a ventilator-dependent child. Qual Health Res [Internet]. 2008 Apr [cited 2012 Aug 09];18(4):501-08. Available from: http://qhr.sagepub.com/content/18/4/501.full.pdf

24. Sono T, Oshima I, Ito J. Family needs and related factors in caring for a family member with mental illness: Adopting assertive community treatment in Japan where family caregivers play a large role in community care. Psychiatry Clin Neurosci [Internet]. 2008 Oct [cited 2012 Aug 09]; 62(5):584–90. Available from: https://auth.ohiolink.edu/DS/?shire=https%3A%2F%2Fjournals.ohiolink.edu%2FShibboleth.sso%2FSAML%2FPOST&target=http%3A%2F%2Fjournals.ohiolink.edu%2Fejc%2Farticle.cgi%3Fissn%3D13231316%26issue%3Dv62i0005%26article%3D584_fnarfialricc&providerId=https%3A%2F%2Fjournals.ohiolink.edu%2Fshibboleth&

25. Hentinen M, Kyngäs H. Factors associated with the adaptation of parents with a chronically ill child. J Clin Nurs [Internet]. 1998 July [cited 2012 Aug 09];7(4):316–24. Available from: http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2702.1998.00154.x/pdf

26. Hopia H, Tomlinson PS, Paavilainen E, Pstedt-Kurki A. Child in hospital: family experiences and expectations of how nurses can promote family health. J Clin Nurs [Internet]. 2005 Feb [cited 2012 Aug 09];14(2):212–22. Available from: http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2004.01041.x/pdf

27. Nuutila L, Salanterä S. Children with a long-term illness: parents' experiences of care. Nurs J Pediatr [Internet]. 2006 Apr [cited 2012 Aug 09];21(2):153-60. Available from: http://www.pediatricnursing.org/article/S0882-5963(05)00292-7/fulltext

28. Cleveland BG. Adaptation to Addison's Disease in a child: a case study. J Pediatr Health Care [Internet]. 2003 Nov/Dec [cited 2012 Aug 09];17(6):301-10. Available from: https://www.amherst.edu/media/view/143474/original/Gance-Cleveland_2003_Journal-of-Pediatric-Health-Care.pdf

29. Ward NJ, Jowsey T, Haora PJ, Aspin C, Yen LE. With good intentions: complexity in unsolicited informal support for aboriginal and Torres Strait Islander peoples. A qualitative study. BMC Public Health [Internet]. 2011 Sept [cited 2012 Aug 09]; 11(686):1-9. Available from: http://www.biomedcentral.com/content/pdf/1471-2458-11-686.pdf

30. Hsiao CY, Riper MV. Individual and family adaptation in Taiwanese families of individuals with severe and persistent mental illness (SPMI). Res Nurs Health [Internet]. 2009 June [cited 2012 Aug 09];32(3):307-20. Available from: http://onlinelibrary.wiley.com/doi/10.1002/nur.20322/pdf

31. Nardi EFR, Oliveira MLF. Conhecendo o apoio social ao cuidador do idoso dependente. Rev Gaúcha Enferm[Internet]. 2008[cited 2012 Aug 09];29(1)47-53. Available from: seer.ufrgs.br/RevistaGauchadeEnfermagem/article/download/.../2997

32. Dessen MA, Braz MP. Rede social de apoio durante transições familiares decorrentes do nascimento de filhos. Psic Teor e Pesq [Internet]. 2000 Sept/Dec [cited 2012 Aug

09];16(3):221-31. Available from: http://www.scielo.br/pdf/ptp/v16n3/4809.pdf

33. Silveira CL, Budó MLD, Ressel LB, Oliveira SG, Simon BS. Apoio social como possibilidade de sobrevivência: percepção de cuidadores familiares em uma comunidade remanescente de quilombos. Cienc Cuid Saude [Internet]. 2011 July/Sept [cited 2012 Oct 03];10(3):585-92. Available from: http://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/17190/pdf

34. Burille A, Zillmer JGV, Swarowsky GE, Schwartz E, Muniz RM, Santos BP et al. The support bonds as strategy of the families to deal with the chronic renal disease and the treatment. J Nurs UFPE on line [Internet]. 2010 Jan/Mar [cited 2012 Nov 25]; 4(1):106-11. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/534/pdf_299

35. Garcia RP, Budó MLD, Oliveira SG, Wünsch S, Simon BS, Silveira CL. Burden of family caregivers of chronic patients and the social support networks. R pesq cuid fundam Online [Internet]. 2012 Jan/Mar [cited 2012 Aug 14]; 4(1):2820-30. Available from: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1656/pdf_497

36. Brondani CM, Beuter M. A vivência do cuidado no contexto da internação domiciliar. Rev Gaúcha Enferm [Internet]. 2009 June [cited 2012 Sept 01]; 30(2):206-13. Available from: http://seer.ufrgs.br/RevistaGauchadeEnfermagem/article/view/7435/6677

37. Lacerda MR, Oliniski SR. O familiar cuidador e a enfermeira: desenvolvendo interações no contexto domiciliar. Acta Scientiarum. Health Sciences [Internet]. 2004 [cited 2012 Aug 14];26(1):239-48. Available from: http://periodicos.uem.br/ojs/index.php/ActaSciHealthSci/article/view/1699/1078

Submission: 2012/12/13
Accepted: 2013/04/07
Publishing: 2013/05/15

Corresponding Address

Bruna Sodré Simon
Rua Bento Gonçalves, 1397 / Centro
CEP: 97450-000 – Cacequi (RS), Brazil