

"Always helping with one thing or another": social network of the family of people with ostomy****"Sempre ajudando em uma coisa ou outra": rede social da família da pessoa com estomia***

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ABSTRACT

A qualitative descriptive exploratory study that analyzed the social network of the families of ostomized patients. This study was conducted at the homes of seven families with ostomized patients, totaling 16 people. Data were collected using a semi-structured interview, a minimum map of relationships and simple observation with records in a field log. Data were evaluated via thematic content analysis. The social network is comprised of the family members; friends and neighbors; health professionals and services; groups of contacts and religious congregations. The webs of this network allow families to recognize their self-image, well-being, type of care, coping and adaptation in crisis situations. However, when analyzing health services, a gap was identified, showing the difficulties of receiving services from the health units in their regions, so they are dependent on support and care from specialized services.

Descriptors: Social Support; Ostomy; Chronic Disease; Family Health; Nursing.

RESUMO

Pesquisa exploratória e descritiva, com abordagem qualitativa, com o objetivo de conhecer a rede social da família da pessoa com estomia. O estudo foi realizado no domicílio de sete famílias de pessoas com estomias, totalizando 16 pessoas, na coleta de dados utilizou-se entrevista semiestruturada, Mapa Mínimo de Relações e observação simples com registro em diário de campo. Os dados foram trabalhados pela análise de conteúdo temática. A rede social é composta pela família; amigos e vizinhos; profissionais e serviços de saúde; grupos de convivência e congregações religiosas. O tecer dessa rede, possibilita para as famílias o reconhecimento da autoimagem, o bem-estar, modo de cuidado, enfrentamento e adaptação em situações de crise. Porém, ao abordar os serviços de saúde, identificou-se uma lacuna, apontando para as dificuldades de serem atendidas nas unidades de saúde do seu território de abrangência, ficando dependentes dos cuidados e apoios do serviço especializado.

Descritores: Apoio Social; Estomia; Doença Crônica; Saúde da Família; Enfermagem.

INTRODUCTION

Health problems involve constant changes, and the increase of non-communicable chronic diseases is the main alteration to the health profile of the population. Ostomy is inserted in this scenario, and its main causes are inflammatory and congenital diseases, traumas and neoplasms⁽¹⁾.

Living with ostomy causes biopsychosocial changes in patients and in their families, considering that the effects of neoplasm are multifaceted and affect the family⁽²⁻³⁾. With the suffering, family members seek solutions to find meaning in the routine⁽²⁾. To help and provide care to the person with ostomy, families search for support, seeking in themselves and in social networks to strengthen its development, to keep self-esteem and face the painful and difficult moments⁽⁴⁾.

A personal social network refers to all relationships that an individual considers important, established through family, friendship, work and study connections, as well as participation in community and religious groups and affinities built during life⁽⁵⁾.

These relationships offer support to families, provide information about how to handle the disease, help in adaptations⁽⁶⁻⁸⁾, and reduce the care load⁽⁷⁻⁹⁾.

Individuals are arms of their families, and nursing professionals have to incorporate the family core into their actions to know the family structure, its relationships and social networks. It allows the development of links with these networks and improvements in family care during the health problem and adaptation⁽¹⁰⁾.

The possibility to reflect about and plan new health actions is based on understanding these relationships⁽¹¹⁾. This study is justified by the increasing number of people with ostomy, the importance of social networks to cope with chronic conditions, and by the fact that nurses have to recognize this context and understand that, being close social networks, it is possible to readapt their practices.

In addition, the state-of-the-art⁽¹²⁾ has demonstrated gaps in the production of national and international knowledge about the social network of the families of ostomized people. Studies involving social networks are conducted especially with family members of children with chronic conditions.

Therefore, the question is: What is the social network of a family whose member was submitted to ostomy? The objective of this study was to learn the social network of families of ostomized people.

METHODS

A qualitative descriptive exploratory study with seven families of people with ostomy, totaling 16 interviews conducted at their homes between January and April 2013. The development of the study complied with the Brazilian legislation for research with humans and was approved by the Research Ethics Committee of the supporting university, under protocol number 171.345.

The families were selected via contact with the ostomized people who were seeking for pouches or an appointment with the multiprofessional team from the Health Care Service to Ostomized People (SASPO) from the Secretariat of Health of a municipality located in the state of Rio Grande do Sul. At this place, the clinical records were read to verify whether the person had a permanent, intestinal or urinary ostomy for more than six months and if the person lived in the municipality. The ostomy time was established, as it is believed to influence the interpersonal relationships of the family of the ostomized person, considering that, a person with ostomy for less than six months could be still in adaptation process and find it difficult to report who has provided care.

The person with ostomy was then invited to participate in the study and suggested family members who could provide information. Thus, the family members considered in this study were consanguineous, or had marriage, adoption, or

friendship connections⁽¹³⁾.

Data collection was previously scheduled via telephone contact. After arriving at their homes, the researchers read the free and informed consent term to each participant, who signed it in two copies, one for the investigator and another for the family members.

The family members had to be over 18 years old and live in the municipality where the study was conducted. People with no verbal communication were excluded. The presence of at least two people was required to characterize a family at data collection⁽¹³⁾, and the person with ostomy could be one of them.

Data were collected by the researcher and a research assistant, using a semi-structured interview, a minimum map of relationships (MMR)⁽⁵⁾ and simple observation with records in a field log. With previous consent from interviewees, the interviews were recorded in a digital recorder and then transferred to a computer and transcribed. The MMR was developed at the end of the interview and its design was made available to participants for filling quadrants and circles.

The MMR was comprised of four quadrants, which represented the social relationships of the family; friendships; community relationships; and belief systems. The latter was subdivided into health systems and social agencies; and work or study relationships. Three concentric circles cover the quadrants which, the closer to the center, the higher the degree of commitment of relationships⁽⁵⁾.

Thematic content analysis identified the themes to build the “coding units” that comprised the study category. The three stages of this analysis were conducted: pre-analysis; material exploration; and treatment and interpretation of results⁽¹⁴⁾. After exhaustively reading the interviews, the coding units received a chromatic code and then the familiar themes were grouped into friends and neighbors;

health professionals and services; supporting groups; and religious congregations; thus, creating the study category, the personal social network. After that, the analysis process was initiated with subsequent discussion with other authors.

Anonymity was preserved in result presentation, adopting identification codes with the letter F (family) plus a number from 1 to 7 corresponding to the order of data collection, degree of relationship of the family member, and PE for person with ostomy.

RESULTS AND DISCUSSIONS

First, the analyzed families were characterized, then their social networks were described. This network was weaved by the family members, friends and neighbors, health professionals and services, supporting groups, and religious congregations.

Family characterization

Of the 16 participants, 10 were female; and their age ranged between 18 and 79 years. Of all seven families that were analyzed, the person with ostomy had no marital status connection at the time of interview in only two families: one was separated and one was single.

Among the ostomized people, most were male, the ostomy time varied from eight months to 12 years and five months; with prevalent cancer/tumors in four cases as the ostomy cause; five had a colostomy (Table 1).

This profile is similar to studies showing that most people with ostomy are male⁽¹⁵⁾; ostomy owing to oncologic disorders⁽¹⁴⁻¹⁵⁾, with female family members providing care⁽¹⁵⁻¹⁶⁾.

Table 1: Characterization of interviewed families from a municipality in southern Brazil, Rio Grande do Sul, Brazil, 2013.

Family	Members	Sex	Age	Marital status	Occupation	Ostomy type/reason/time
F1	PE	F	37y	Separated	Retired	Colostomy (4y)
	Daughter-a	F	20y	Single	Unemployed	Crohn's disease
	Daughter -b	F	18y	Married	Unemployed	
F2	PE	M	75y	Married	Retired	Colostomy (11y)
	Wife	F	39y	Married	Housekeeper	Intestine cancer
F3	PE	M	44y	Married	Manager	Colostomy (8m)
	Wife	F	41y	Married	Accounting assistant	Rectal tumor
F4	PE	M	55y	Married	Retired	Urostomy (1y9m)
	Wife	F	48y	Married	Retailer	Intestine cancer *
F5	PE	M	42y	Single	Retired	Urostomy (8y)
	Mother	F	63y	Widowed	Pensioner	Neurogenic bladder
F6	PE	M	79y	Married	Retired	Colostomy (6y)
	Wife	F	76y	Married	Retired	Intestine cancer
F7	PE	F	58y	Married	Retired	Colostomy (12y5m)
	Husband	M	61y	Married	Retired	Bowel polyp
	Friend	F	49y	Married	Secretary	

Legend:

PE: person with ostomy;

F: female;

M: male;

y-year;

m-months;

* surgical complication in temporary colostomy reconstitution due to intestine cancer.

Personal social network

When asked about who the participants could count on in providing care to their relative with ostomy, the unanimous answer was the family members. The personal social network was mainly comprised of **the family itself**.

On ourselves! We never count on anybody else. (F1 – daughter - a)

Now, I have only (the husband), but before I had the children. The support is good, they have always provided support. (F7-PE)

The testimonials showed the network is comprised of children and spouses, and the support received was characterized as strong. The interviewees highlighted that, in moments they required help, the family core supported them.

Such fact was found in other studies involving family members of people with chronic conditions^(8,17).

Permanent ostomy is characterized as a chronic health condition, requiring daily and continuous care. For this reason, biopsychosocial and emotional stress are identified; however, the family is an essential source of support to the person with ostomy⁽¹⁸⁾, helping face stress, and physical and psychological challenges⁽¹⁷⁾.

This fact is observed in the records from the field log:

During the interview, Mr. (F2-PE) and Mrs. (F2- wife) exchanged affectionate looks and demonstrations. They had a clearly harmonious relationship, with the wife as care provider. (Field log 14/01/2013)

The social network also includes other family members, such as **siblings, grandparents and uncles/aunts**:

My mother's brother and our grandmother help with what they can, support to encourage! (F1- daughter-a)

We are from (birth city), then they (family members) were here, those not living in the city called, my sisters came here for a while, they stayed a couple of days with me. Then, our family is his brother and sister who were with us. (F3-wife)

I have an aunt who would arrive before me at the hospital for every little thing I had to do. She knew I didn't have my mother anymore, she played my mother's role. (F7-PE)

Social network weaving occurs with the aim to be present, physically or not, as noted in the testimonial of F3-wife.

Men with cancer say physical presence is not necessary, but otherwise knowing they can count on someone when required⁽¹⁹⁾. When a disease occurs in a family, everyone wants to help at difficult times⁽²⁰⁾, as observed in the testimonials.

There are also **non-consanguineous** family interrelationships:

I can count on my child's godmother! Her support is strong, all surgeries he had, she was there, she left her family to go to Porto Alegre with me. (F5-mother)

Whenever I need, I can count on my brother-in-law. (F4-wife)

[...] would be the closest people. And my aunt (name), right? She is a friend of ours (F3-wife)

The social network comprised of their child's godparents, brother/sister-in-law and friends is mentioned as providing strong support, being close at difficult times and helping in all situations. With hospitalization, the social network was consolidated.

A study conducted with family members of patients with chronic conditions showed that family relationships are usually stronger when a member has to be hospitalized⁽²⁰⁾.

Friends are incorporated into the family core, exceeding the old concept of family and showing an

evolution of society. This perception agrees with the family concept used in this study, which goes beyond consanguineous ties and includes everyone considered as family⁽¹³⁾.

With these findings, the social network is comprised of three family bases: nuclear, extended and expanded. The nuclear sphere includes children and spouses, the extended sphere includes parents, grandparents and siblings, and the expanded sphere includes those with no consanguineous ties. Such diversity is favorable, since the family acts as a link between the threads weaving this network, favoring quality of life and well-being⁽¹⁰⁾.

Other friends and neighbors appeared as social relationships in situations of health problem and consequent ostomy construction and adaptation:

Our neighbor in (place they lived) gave us support. (F1-daughter b)

That friend was very good, he helped anytime we needed, but he died. (F4-wife)

During treatment with chemotherapy and radiotherapy, they (friends) picked me up. My wife didn't have to worry about that, they picked me up and took me there. (F3-PE)

When effective, relationships are remembered even when the contact no longer exists with the network members, for instance, after moving to another place or dying. Yet, the friendship was stronger, making friends feel they wanted to be present in situations the family needed some help.

Friends and neighbors are part of the social network of families with chronic health problems^(8,10,17-18), helping overcome problems and changes resulting from the disease^(10,18).

Health professionals and services were part of the social network. The ostomy nurse and physicians were mentioned as important in social networks.

My reference is (the ostomy nurse). We feel attached to people because that person helped in that moment we needed. The greatest help was hers, I call her for anything I need. She became a great friend, she can't be forgotten! (F7-PE)

Regarding the physicians, (urologist's name) helped me a lot! They (the proctologists) talked to each other. If it wasn't for their referrals, I wouldn't be here today. (F4-PE)

The ostomy nurse from SASPO was mentioned in all interviews as an important member of the interviewees' social networks, due to her support and guidance.

A study conducted to analyze how nursing can promote family health during the health problem of a family member identified the relevance of being present and providing information related to home care⁽²¹⁾.

The interviewees perceived the expressive behavior of physicians while correctly performing the surgery, in their referrals and because they cared about the patient after the ostomy construction.

Health professionals have an essential role in providing information in case of a chronic disease, as this is a new experience that causes questioning of family members⁽²²⁾. In this context, health professionals have to respect cultural diversities, joining professional and family knowledge to ensure quality of life, an efficient therapy, to and strengthen social connections⁽²³⁾.

Regarding health services, the interviewees reported network weaving happens at different **healthcare levels**.

When I need some healthcare and I can't go there (SASPO), then I go to the basic health facility near here. There's a FHP (Family Health Program Center) here, the doctor is aware of the things he does, she's a

clinician, then she sends me to another place. (F5-mother)

I get the medicine there, at (Basic Health Facility). I have the appointments there and get my prescription. I go there just for the medicine. (F6-PE)

Outside, at (public hospital) the proctology service is wonderful. It takes a long time, but it's very good. (F1-PE) I go straight to (private hospital), they provide all support. (F2-wife)

In primary care, the Family Health Strategy was reported as a reference place for the son, according to F5-mother, as the physician had followed the entire process of the health problem, helping when a referral was required. On the other hand, the basic health facility in the district is mentioned for prescriptions or medications. The primary health care service does not offer effective care to ostomy. However, it is mentioned because of other services. It should offer general service, but health professionals have to be prepared to provide basic care to chronic conditions, such as ostomy, as this service should be a reference to the territory.

In tertiary care, public and private hospitals of the city are mentioned. Even with the Unified Health System taking a long time to provide services, F1-PE classifies it as good. Using the expression "every support", we conclude the interviewees refer to the problem-solving ability at the tertiary care level, in urgent cases, emergency and treatment follow-up.

A study conducted with chronic respiratory disease patients also showed the recognition of primary and tertiary health care professionals and services in social networks, highlighting the service provided by basic health facilities⁽¹⁷⁾.

It does not agree with the testimonials of participants, as they do not find the required support to obtain health care in these places:

When (F6-PE) mentioned the basic health facility near home, (F6-wife) was restless, she stood up and repeated several times: "it's no use going there, they never have anything for this (pointing the ostomy), they send us directly to an emergency care unit". (Field log, 04/26/2013)

The care provided by health professionals and services is against health policies, as the basic health facility near F6-PE's home sent him to an emergency care unit, showing no continuity in care provision through this professional network.

Supporting groups help people with ostomy and their family in handling the new situation:

Some days you feel depressed, you go to this group (people with ostomy) and then you see you're not the only one carrying that thing. (F1-PE)

The supporting group (people with ostomy) and the meetings provide strong support. There's a psychologist, it's very good, because it's a brotherhood! (F2-PE)

I never miss it, it's very good! There are workshops, we go there, have some fun, have a chat. They (people with cancer) show their cancer, she (ostomy nurse) is more for (pouch change). (F4- PE)

The social network of the supporting groups is comprised of two segments: one for people with ostomy, from the Municipal Association of Ostromized People, a service provided in a partnership with SASPO; and one for people with cancer. When attending these groups, they see other people are also going through the same chronic problem, a fact that may help develop a "brotherhood", as they present a common characteristic: living with an ostomy.

Besides this feeling of congregation, the groups answer questions related to the disease and care; promote the exchange of experiences and lessons; allow social integration and receive suggestions for

pouches and meeting themes.

The meetings promoted by the Municipal Association of Ostromized People are a moment to seek for information, positive collaboration to recovery and security, based on reliable dialog, with the identification of the consequences from the health condition⁽²⁴⁾. The possibility to overcome this social isolation⁽⁸⁾ and participate in a social activity⁽¹⁵⁾ are mentioned as the main benefits of the supporting groups for family members of people with a chronic disease.

These supporting groups can also be related to a collective place, that is a "place that should be built by social actors, strengthening the aspects of participation and development of strategies for the common good"⁽¹¹⁾. In the opinion of the interviewees, common good means shared lessons about how to live with an ostomy.

Religious congregations are also elements of the social network:

We have the people from the church, the church administration, the pastor! Spiritual and moral support. A divine help is great. I won't tell you that one swallow doesn't make a summer, but it does! We are kind of alone in the world and we don't need it, thank God. (F4-PE)

[...] I'm religious, I live with the strength of religion, because if we don't hold on that power of God, what else will we hold on to? (F6-wife)

Religious institutions and their followers, regardless of the type of belief, are an important element in social network. Families seek in religion/spirituality the help to handle health problems and courage to keep ahead. They say divine help is essential, and they feel good because of that, comforting them in living with an ostomy.

National^(2,10,15,17-18) and international⁽⁸⁾ studies with family members of patients with chronic diseases report

that, to face the challenges from chronic health problems and keep emotional balance, they seek in faith the support to keep ahead and adapt to this lifestyle.

CONCLUSION

The social network of these families is organized by different webs comprised of the nuclear, extended and expanded families. Every family is single and include culturally similar beings, who weave their relationships according to the way they handle chronic health problems. Such fact allows to build true webs with ties, allowing to exchange support and strengthen relationships, supporting the family in care provision. However, when addressing health services, a gap is seen in most networks of families, as they face challenges to be assisted at basic health facilities near home, becoming dependent on the care and support provided by specialized services.

With the care provided by the ostomy nurse from SASPO, relationships of strong support were created, showing the recognition of a service concerned about the

well-being of these people. The identification of the elements of the social network of families may lead nursing to have its own webs of relationships with these elements and family members, favoring the exchange of experiences to improve service provision.

Therefore, a favorable value was observed in the webs of these social networks, as they allow to recognize the self-image, well-being, type of care, coping and adaptation in situations of chronic diseases. This study brought out moments of reflection in the studied families about their relationships, as during the interview, and especially in the development of the minimum map of relationships, they had a chance to recall moments they have experienced and realize the importance of effective links to handle this chronic condition.

This study indicates that further research on this theme is required, even using a quantitative perspective, to evaluate the support offered by social networks, as there are scales that may help in this process and complement qualitative data.

REFERENCES

1. Gemelli LMG, Zago MMF. A interpretação do cuidado com o ostomizado na visão do enfermeiro: um estudo de caso. *Revista Latino-americana de Enfermagem*. [Internet]. 2002 [acesso em: 28 nov 2013];10(1):34-40. Disponível em: <http://www.scielo.br/pdf/rlae/v10n1/7769.pdf>.
2. Angelo M. Ouvindo a voz da família: narrativas sobre sofrimento e espiritualidade. *Mundo Saúde*. [Internet]. 2010 [acesso em: 28 nov 2013];34(4):437-43. Disponível em: http://www.saocamilo-sp.br/pdf/mundo_saude/79/437a443.pdf.
3. Vestena Zillmer JG, Schwartz E, Burille A, Linck C de L, Lange C, Eslabão A. Vínculos de los Clientes oncológicos y familiares: una dimensión para ser observada. *Enferm. glob.* [Internet]. 2012 [acesso em: 01 nov 2013];1(25):37-44. Disponível em: <http://revistas.um.es/eglobal/article/view/143071>.
4. Brusamarello T, Guimarães AN, Labronici LM, Mazza VA, Maftum MA. Redes sociais de apoio de pessoas com transtornos mentais e familiares. *Texto & contexto enferm*. [Internet]. 2011 [acesso em: 01 nov 2013];20(01):33-40. Disponível em: <http://www.scielo.br/pdf/tce/v20n1/04.pdf>.
5. Sluzki CE. Personal social networks and health: conceptual and clinical implications of their reciprocal impact. *Fam. syst. healt.* [Internet]. 2010 [acesso em: 21 nov 2013];28(1):1-18. Disponível em: <http://www.apa.org/pubs/journals/features/fsh-28-1-1.pdf>.
6. Barrera-Ortiz L, Carrillo-González GM, Chaparro-Díaz L, Afanador NP, Sánchez-Herrera B. Soporte social con el uso de TIC's para cuidadores familiares de personas com enfermedad crônica. *Rev. salud. pública*. [Internet]. 2011 [acesso em: 21 nov 2013] 13(3):446-57. Disponível em: <http://www.scielo.org.co/pdf/rsap/v13n3/v13n3a07.pdf>.
7. Nóbrega VM, Collet N, Silva KL, Coutinho SED. Rede e apoio social das famílias de crianças em condição crônica. *Rev. eletrônica enferm*. [Internet]. 2010 [acesso em: 20 out 2013];12(3):431-40. Disponível em: <http://www.revistas.ufg.br/index.php/fen/article/view/7566/7859>.
8. 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. paediatr. neurol.* [Internet]. 2011 [acesso em: 20 nov 2013];15:21-28. Disponível em: [http://www.ejpn-journal.com/article/S1090-3798\(10\)00142-X/fulltext](http://www.ejpn-journal.com/article/S1090-3798(10)00142-X/fulltext).
9. Yey LL, Shi-Kai L, Hai-Gwo H. Needs and demands for community psychiatric rehabilitation programs from the perspectives of patients and caregivers. *Community Ment. health j.* 2010;47:415-23.
10. Di Primio AO, Schwartz E, Bielemann VLM, Burille A, Zillmer JGV, et al. Rede social e vínculos apoiadores das famílias de crianças com câncer. *Texto & contexto enferm*. [Internet]. 2010 [acesso em: 25 out 2013];19(2):334-42. Disponível em: <http://www.scielo.br/pdf/tce/v19n2/15.pdf>.
11. Budó MLD, Oliveira SG, Garcia RP, Simon BS, Schimith MD, Mattioni FC. Redes sociais e participação em uma comunidade referenciada a

- uma Unidade de Saúde da Família. *Rev. gaúch. enferm.* 2010;31(4):753-60.
12. Simon BS, Budó MLD, Garcia RP, Gomes TG, Oliveira SG, et al. Rede de apoio social à família cuidadora de indivíduo com doença crônica: revisão integrativa. *Rev enferm UFPE on line. [Internet].* 2013 [acesso em: 29 mar 2015];7(esp):4243-42. Disponível em: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/viewFile/4181/pdf_2644.
13. Wright LM, Leahey M. Enfermeiras e famílias: um guia para avaliação e intervenção na família. [trad. Sílvia Spada]. 4 est ed. São Paulo: Roca; 2008.
14. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.
- 15- Lenza NFB, Sonobe HM, Zago MMF, Buetto LS. Características socioculturais e clínicas de estomizados intestinais e de familiares em um Programa de Ostomizados. *Rev. Eletr. Enf. [Internet].* 2013 [acesso em: 29 mar 2015];15(3):755-62. Disponível em: <http://dx.doi.org/10.5216/ree.v15i3.17594>.
16. Souza JL de, Gomes GC, Xavier DM, Alvarez SQ, Oliveira SM. O preparo do familiar para o cuidado à pessoa com estomia. *Rev enferm UFPE on line. [Internet].* 2013 [acesso em: 29 mar 2015];7(1):649-56. Disponível em: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/download/3731/5628>.
17. Souza SS, Vieira FA, Kerkoski E, Silva DMGV, Meirelles BHS, Baptista R, et al. Redes sociais de pessoas com problemas respiratórios crônicos em um município do sul do Brasil. *Cogitare Enferm. [Internet].* 2009 [acesso em: 08 nov 2013];14(2):278-84. Disponível em: <http://ojs.c3sl.ufpr.br/ojs2/index.php/cogitare/article/view/15619>.
18. 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. *Rev. enferm. UFPE on line. [Internet].* 2010 [acesso em: 08 nov 2013];4(1):106-11. Disponível em: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/viewFile/534/pdf_299.
19. Feijó AM, Schwartz E, Muniz RM, Santos BP, Viegas AC, Lima LM. As inter-relações da rede social do homem com câncer na perspectiva bioecológica: contribuições para a enfermagem. *Texto & contexto enferm. [Internet].* 2012 [acesso em: 16 out 2013];21(4):783-91. Disponível em: http://www.scielo.br/scielo.php?pid=S0104-0707201200040008&script=sci_arttext.
20. Garcia RP, Budó MLD, Oliveira SG, Wünsch S, Simon BS, Silveira CL. Sobrevida de cuidadores familiares de doentes crônicos e as redes sociais de apoio. R. pesqui. cuid. fundam. (online) [Internet]. 2012 [acesso em: 16 out 2013];4(1):2820-30. Disponível em: <http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1656>.
21. 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 [acesso em: 16 out 2013];14(2):212–22. Disponível em: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2004.01041.x/pdf>.
22. Silveira CL, Budó MLD, Ressel LB, Oliveira SG, Simon BS. Apoio social como possibilidade de sobrevida: percepção de cuidadores familiares em uma comunidade remanescente de quilombos. *Cienc. cuid. saúde.* 2011;10(3):585-592.
23. 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 AJ, Marcon SS, editors. *Enfermagem à família: dimensões e perspectivas.* Maringá: UEM; 2011. p.73-85
24. Silva AL, Shimizu HE. A relevância da rede de apoio ao estomizado. *Rev. bras. Enferm. [Internet].* 2007 [acesso em: 26 out 2013];60(3):307-11. Disponível em: <http://www.scielo.br/pdf/reben/v60n3/a11.pdf>.