

Meeting at home: a proposal of home attendance for families of dependent seniors*

Encontrando-se em casa: uma proposta de atendimento domiciliar para famílias de idosos dependentes

Encontrándose en casa: una propuesta de atención en el domicilio para las familias de ancianos dependientes

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ABSTRACT

Objective: This qualitative study intends to identify how a family system reacts before the situation of dependence of a senior family member, which resources it uses to maintain the stability and the nursing attendance made available in this context. **Methods:** The approach of the family systems was used as the theoretical reference, and action-research as the method. The data were collected in the period from November/2004 to January/2005, through the construction of a genogram, an ecomap and problem definition. **Results:** Main family demands: anticipated mourning, overload on the role of caregiver, lack of knowledge regarding the disease and family maladjustment before the crisis. Main interventions: motivating the family to speak openly about the illness, offering suggestions and information, praising the family strength and ensuring prompt service. **Conclusions:** With family attendance as the systemic focus, it was possible to propose healthcare interventions to improve the quality of family life so as they could devise their own solutions to face adversities.

Keywords: Family relations; Homecare nursing; Old age assistance; Family nursing

RESUMO

Objetivo: Este estudo qualitativo teve por objetivo descrever como um sistema familiar reage perante a situação de dependência em um membro idoso, quais recursos utiliza para manter sua estabilidade e a assistência de enfermagem disponibilizada neste contexto. **Métodos:** Utilizou-se como referencial teórico a abordagem dos sistemas familiares e como método a pesquisa-ação. Os dados foram colhidos de novembro de 2004 a janeiro de 2005, utilizando-se o genograma, o ecomapa e o levantamento de problemas. **Resultados:** Principais demandas familiares: luto antecipado, sobrecarga do papel de cuidador, falta de conhecimento sobre a doença e desajustamento familiar perante a crise. Principais intervenções: incentivar a narrativa da enfermidade, oferecer sugestões e informações, elogiar as forças familiares e assegurar pronto atendimento. **Conclusões:** Com o atendimento à família sob o enfoque sistêmico foi possível propor as intervenções de ajuda para a melhoria da qualidade de vida familiar, de maneira que ela também vislumbresse suas próprias soluções para o enfrentamento das adversidades.

Descritores: Relações familiares; Assistência domiciliar; Assistência a idosos; Enfermagem familiar

RESUMEN

Objetivo: En este estudio cualitativo se tuvo como objetivo describir cómo un sistema familiar reacciona frente a una situación de dependencia de un miembro anciano, qué recursos utiliza para mantener su estabilidad y la asistencia de enfermería disponible en este contexto. **Métodos:** Se utilizó como referencial teórico el abordaje de los sistemas familiares y como método la investigación acción. Los datos fueron recogidos desde noviembre del 2004 a enero del 2005, utilizándose el genograma, o ecomapa y el levantamiento de problemas. **Resultados:** Principales demandas familiares: duelo anticipado, sobrecarga del papel de cuidador, falta de conocimiento sobre la enfermedad y desajuste familiar frente a la crisis. Principales intervenciones: incentivar a la familia a la narración de la enfermedad, ofrecer sugerencias e informaciones, elogiar las fuerzas familiares y asegurar la atención rápida. **Conclusiones:** Con la atención a la familia bajo el enfoque sistêmico fue posible proponer las intervenciones de ayuda para la mejoría de la calidad de la vida familiar, de manera que ella también vislumbre sus propias soluciones para el enfrentamiento de las adversidades.

Descritores: Relaciones familiares; Asistencia domiciliar; Asistencia al anciano; Enfermería familiar

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INTRODUCTION

In Brazil, population aging shows peculiar characteristics, given its speed. According to standards established by the World Health Organization, the country may be already considered structurally aged, since over 7% of its population is, as of today, 60 years of age or older⁽¹⁾.

Such demographic change highlights aging in the national scenario, where not only biological aspects of old age, but cultural aspects are also considered⁽²⁾.

At this stage of life, there are functional alterations that, although varying from one individual to the next, are found in all seniors and are characteristic of the natural process of aging, thus bringing a higher predisposition for the onset of chronic health conditions and their possible debilitating sequelae. Therefore, it is expected that the number of handicapped seniors inserted in the social and family environments would increase.

The reduction of costs in hospital and institutional care is one of the reasons that causes the recommendation of the permanence of handicapped seniors in their own homes, both in Brazil and in many other countries, under the care of their own families. Moreover, the current view of healthcare assistance proposes that a disabled elder struck by a chronic condition and must be cared for in the environment where he/she has always lived, and where he/she became sick.

Yet, such attitude may be considered rather idealistic, since the families have been constantly changing in modern society, and may not always be able to afford taking on healthcare responsibilities towards their seniors. As an example, this may require one member of the family to quit his/her job.

Besides, the fact of experiencing the possibility of loss may also be an aspect that makes healthcare difficult for the family member if the senior has certain values about his body and does not feel comfortable being bathed by a daughter, for example. These examples show that, to be able to care for their elder, the family must be included in the health professional's plan of care; it is necessary to adopt measures such as establishing resting hours and moments when healthcare should be provided by professionals. This paper aims to present a nursing intervention based on the Calgary model, which adopts the family as a healthcare unit.

When the family is considered as a system, i.e., a unit where it is possible to visualize the interaction among its members, the presence of a handicapped elder affects all the group members, and, depending on the family culture, aging and disability are seen in many different ways. Hence, the health professionals need to take the structure and culture of the family into consideration when proposing healthcare actions for the elder.

As such, the objective of this study was to describe how a family reacts when facing the situation of disability in a senior member, which resources are used to maintain its own stability and which nursing interventions may be useful and applicable in this context.

METHODS

In this qualitative study, the theoretical reference used was the approach of the family systems in the systemic reference⁽³⁾ and research-action was adopted as a work method, where researchers and participants representative of the situation or the problem are involved in a cooperative and participative way⁽⁴⁾. We used a relatively simplified assessment and intervention model based on the Calgary model. After studying the model and the form that derives from it, we chose a family with whom the model would be applied to guide the assessment of the family and the nursing interventions adopted.

One of the authors responsible for the development of the meetings (herein named lead researcher) and a supervisor, also a co-author of the study took part in this experience, along with three members of a family unit with a female handicapped senior with mental disease – schizophrenia – for over 20 years and chronic renal insufficiency, diagnosed three months before, assisted by a Family Health Unit (USF) of the interior of the state of São Paulo.

After being approved by the Committee of Research Ethics of the Medical College of Botucatu – UNESP, in the period from November/2004 to January/2005, the data were collected in five meetings at the family's household, through the drafting of the genogram, ecomap, the outlining of problems and the field journal for the registry of interactions. The data obtained were analyzed in accordance to the interactive model of data analysis⁽⁵⁾.

RESULTS

It should be pointed out that each of the participants received a fictitious name, in order to preserve their identity.

Introducing Ms. Alice's family

Ms. Alice's family was reached through the community health agent who reported the insistence of the patient's daughter in having home visits. She is dependent of healthcare for having been struck by kidney disease for three months.

According to the agent's verbalization, Ana, the daughter, insistently sought the service claiming that it was the PSF's duty to come to their house to see her mother, since they offer medical healthcare at home.

However, every time the team went to the household, they verified that the senior's state of health was satisfactory, and healthcare other than that already in place was not necessary.

As such, according to the agent, when the team performed a home visit, they could verify that Ms. Alice had clinical and laboratorial exams within acceptable standards for her ailment, and her daughter's insistence for visits was deemed unnecessary. It was then necessary to know and to understand which other reasons could be related to the summoning of the PSF team by the patient's daughter.

Such situation represents our warning about the idealized view of the family held by the professional. We chose this family because, despite offering a trip to the household, the health professional did not see to the verbalized needs of the daughter; she would keep going to the PSF to request visits.

Our first intervention, then, was to talk to Ana, the daughter, instead of seeing the senior. At this moment, we broadened our focus and adjusted our lenses to the context of the senior. Inclusion and listening are powerful interventions in this moment⁽³⁾.

Five meetings were held with Ana* – patient's daughter; Mr. Alberto* – Ana's husband; Ângela – Ana's niece; the researching nurse and the supervising psychiatric nurse. Ana was the only one to participate in all five meetings.

The family structure

The patient, Ms. Alice, is 61 years old, has shown schizophrenia for 20 years and chronic renal insufficiency, diagnosed three months ago. Her husband, Mr. Benedito, 65, is a retired farm worker. They have one daughter, Ana, 29, an unemployed household maid, who is married to Alberto, 24, a delivery person. Together they have two children: Bruno, 7, and Alfredo, 2. From this information, the genogram (Figure 1) was drawn, aiming to understand the internal structure of Ms. Alice's family.

The family relations to broader systems, i.e., its external structure, were verified with the construction of the ecomap (Figure 2)

Ms. Alice has hemodialysis sessions three times a week at the university hospital, this being her only outing. Mr. Benedito usually goes to a bar downtown, where he meets his friends. He also goes to the bank to receive his pension money and to the USF when he feels "ill".

Ana usually goes to the USF to check on her own health and her children's, and, when she has a jog, keeps a bond with her workplace. Alberto's relationships happen with his bar friends and his co-workers. Ana and her husband are in contact with uncles, aunts and cousins on her father's side of the family.

The family lives in an area with relevant socio-sanitary problems and with a low-income population. In their

house territory, there is the house where Ms. Alice lives with Mr. Benedito, and, in the backyard, there is the house where Ana lives with Alberto and their children. Both are simple, have four rooms each, insufficient natural lighting, minimal necessary furniture and satisfactory hygienic conditions.

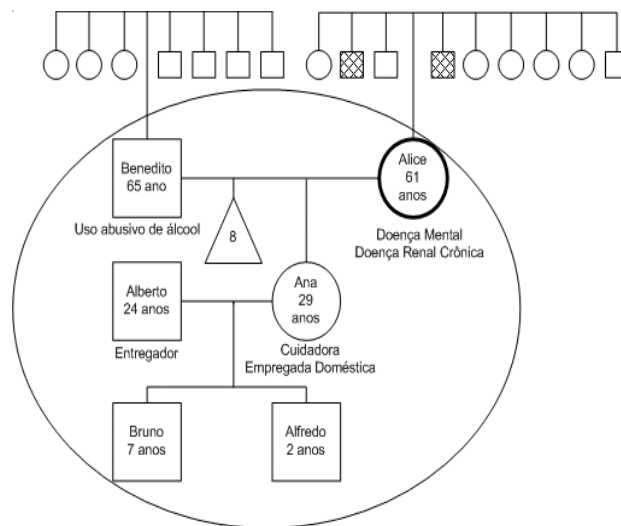








Figure 1 –Alice's Family Genogram

Legend:

- Man 
- Woman 
- Marriage 
- Death 
- Reference Person 
- Abortion 

Adapted from Wright & Leahey, 2002⁽³⁾.

The family group lived off of Mr. Benedito's pension, Alberto's income as a delivery person and Ana's salary as a maid. The family's monthly income was slightly over three minimum salaries.

Mr. Benedito feels well about being able to contribute financially with the household expenses; he is proud of being able to buy medication that is not supplied by the USF, food and clothing for the family.

Ms. Alice and Mr. Benedito have no formal education. Ana and Alberto have incomplete high school education. Ana's eldest son attends the first grade, while her youngest son does not attend school yet.

All members of the family are catholic. Although not churchgoers, they all have faith and resort to God when facing difficult moments.

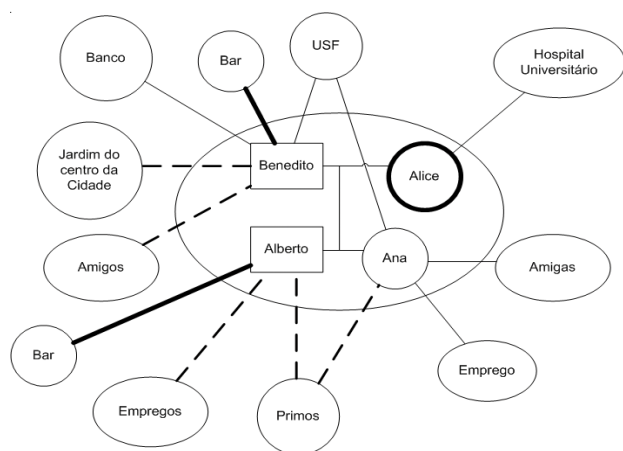


Figure 2 – Alice's Family Ecomap

Legend:

Moderate connection	_____
Strong connection	=====
Very strong connection	=====
Weak connection	-----
Stressful connection	-----

Adapted from Wright & Leahey, 2002⁽³⁾.

Family development

Regarding the family life cycle, i.e., the division in stages of family development, with their repeating of peculiar tasks and models of interaction through the generations, two phases in life stages could be identified: "family with young children" and "family at the later stage of life"⁽⁶⁾. This family is similar to old families, where many generations live together.

Regarding the "family with small children" stage, it is expected that the spouse system joins together in the tasks of bringing the children up, financial and domestic tasks, and that there should be a realignment of the relationships with the extended family to include the roles of parents and grandparents⁽⁶⁾. In the family observed, the responsibility and the response to the children's requests are mostly seen to by Ana, without pressing difficulties.

In the later stage of life, the key principle is to accept the change of generational roles, such as giving a more central role to a younger generation⁽⁶⁾. For this reason, probably, it is important for Mr. Benedito to contribute financially; his contribution places him in an important position, centered on the role of provider.

The development of a hegemonic model of a nuclear family solidifies in most households; male authority concentrates in the head of the family, who asserts its legitimacy by being the financial provider⁽⁷⁾.

Ana recognizes the importance of her father's role. However, she is concerned about his health: he is hypertensive, has glaucoma and abuses alcohol.

There is an appropriate interdependence between the

older generation and the subsequent generation: Mr. Benedito is able to help his daughter and she is responsible for caring for her parents, especially the handicapped mother. Although aging is usually associated to inefficiency, the seniors seem to have the same likelihood of helping and supporting their children, as seen in this study⁽³⁾.

Ms. Alice, in turn, is schizophrenic and is totally dependent on her daughter, especially because of the degenerative aspect of the chronic renal disease, recently diagnosed – Ana relates her mother's nearly-total dependence (not communicating, not bathing and not eating by herself) to the onset of renal insufficiency. From this diagnostic, the family, who had certain stability, starts to crumble: there is a marked overload on the role of caretaker played by Ana, the abusive use of alcohol by Mr. Benedito and the preparation of the family for the loss of the mother.

Although the indication of hemodialysis for seniors with severe cognitive difficulties is object of discussion, this option was chosen by the staff of the university hospital of the city.

For Mr. Benedito, the fact that Ms. Alice goes through the hemodialysis sessions every week only lengthens the suffering of the family, since the kidney disease is already at a late stage. Besides the issue of terminality, i.e., the senior being outside any therapeutic possibility of cure, the family also experiences the issue of mortality, since the patient is found to be at the later stage of life. In this phase, part of the family stress occurs due to the impact of the elder's dependence over the family, and the other part stems from the preparation of the family for her death⁽⁸⁻⁹⁾.

Family functioning

Daily life activities such as eating, hygiene, sleeping, working, child care, among others, add to those related to Ms. Alice's handicaps, seen to by her daughter Ana daily: preparation and feeding of a special diet, bandaging on an intravenous catheter and on a lower limb ulcer, medicating, bathing and hemodialysis three times a week.

Regarding the expressive or affective workings of the family, it could be verified that all of the care offered to Ms. Alice are part of Ana's responsibilities. According to her, her father and her husband would not be able to do it because they are male. This may be explained by the gender issue, permeated by a group of beliefs about the expectations of conduct and male and female experiences⁽³⁾.

Mr. Benedito reported being sad and constantly upset. According to Ana, this happens due to the fact of him not understanding his wife's disease very well and for not being able to bear his son-in-law's habit of listening to loud music. Looking at this relationship between

father-in-law and son-in-law from an interactional perspective, Mr. Benedito feels humiliated and disrespected by his son-in-law and criticizes his behavior. Because of his criticism, he is seen as a curmudgeon upsetting Alberto, who keeps his behavior, ignoring his father-in-law. Ana does not mind the responsibility for caring for her mother, only resenting the fact that her father and husband live in constant conflict. Being an only child, there has been a special care in her opinion so that she could be born, and now she interprets it as being her turn to take care of her mother. This is a belief that has a facilitating role for the development of solutions for the problems.

Introducing the meetings at the household

The first meeting occurred while aiming to start the construction of the genogram, ecomap and outlining of the problems.

At first, Ana mentions not having difficulties to deal with the situation, being sorry for her father being upset, not liking the noise and not talking to his son-in-law. Regarding her husband, she says that he does not feel a strong bond with the family for being younger; he does not see the mother-in-law's problems as being worth of his attention.

Thus, most of Ms. Alice's care has been her responsibility since she was 9 years old. At that time her father was a farm worker and Ms. Alice was haunted by "nervous attacks" and was admitted to psychiatric institutions.

Due to the care she provides her mother with, it is not always possible for Ana to enjoy herself, even though she likes to have friends over to visit. She also finds it difficult to find paying jobs because of her responsibilities towards her mother.

The family problems identified were related to the overload on the role of caretaker played by Ana and the conflicts between father-in-law and son-in-law. The nursing interventions were: discussing the (re)insertion of leisure and work in her life and the setting of limits for her husband and her father, regarding the house and the family relationships.

The second meeting happened while aiming to conclude the genogram, the ecomap and to delve deeper into the discussion of family relations.

Ana reported that, before being born, Ms. Alice had suffered eight abortions and one fetal death for not having medical attention during her pregnancies. When she was impregnated with Ana, she and her husband decided to submit to medical care, so pregnancy and delivery happened normally.

Thus, in Ana's opinion, there was a lot of commitment so she could be born and now she feels obliged to compensate it by caring for her mother. She believes that

God had already drawn this plan and allowed her to be born so she could take care of her mother afterwards, and as such she does it wholeheartedly, only becoming upset with the conflicts between her father and her husband.

It can be noticed that Ana has a conflicting family role, since she is divided between caring for her mother and serving her husband, playing the roles of daughter and wife. Ana's belief in her vocation as a caretaker contributes to her taking responsibility for her mother, however this need does not allow her to admit the need to share her responsibilities with other members of the household.

Ana believes that the emotional overload she is constantly submitted to, due to family conflicts, might trigger some kind of "head problem", like her mother's. For Ana, such a problem could be hereditary, since some family members on her mother's side have also had them. Such concern is intimately related to the anticipated mourning experienced by her family: since the disease has a hereditary characteristic, Ana could be the next to fall ill after her mother's death.

Ana said that she feels sad about not talking to her father so often and, when she does, communication happens in a demanding way, since she wants to know where he had been all day. She mentions that she is worried about her father when he is at the bar and abuses alcohol.

Regarding the changes observed in the family since the previous meeting, Ana reported that she had found a job as a cleaning maid, working three times a week. In these days Mr. Benedito would be responsible for taking care of the children.

The nursing interventions were: completing the drawing of the genogram, ecomap and providing information about the disease, dismissing the belief that it could only be hereditary. Regarding the difficulty of communication between Ana and her father, we suggested her to approach him when he came home not under the influence of alcohol, asking him, for instance, how the outing had been, so that they had an opportunity to talk. The importance of Ana having a regular job has also been highlighted.

In the third meeting Ana mentioned that the relationship between her father and her husband was quieter, and that she was feeling more relaxed as well. She believes this had been possible because of the group's attitude of mutual respect and the homecare, which enabled them to visualize how their interactions could damage the harmony of the group.

Her cousin Ângela reported being worried with the possibility of the second episode of a gynecological infection in the year to evolve to a "serious disease", and, at that, Ana mentioned that, since she had her first child, seven years ago, she feels a lot of pain when engaged in sexual intercourse. She says that, because of the pain, she

is not always able to go through the sexual relation, and that “even though the husband is patient sometimes, he is young”. She remarks having sought several services, and that she has always followed the medical directions, but to no avail.

The following interventions were performed: Pointing out that Ana’s initiative to have a job outside the home was very important for the standards of family relations and advising the cousin that it would be necessary to prioritize the proper treatment of her infection, and to check the possibility of gynecological care as soon as possible. We have also discussed briefly the possibility that Ana, after the ending of the sessions, could use some psychotherapy, where she could rethink her relationships with her parents and her husband, for example.

The fourth meeting was held while aiming to have an in-depth discussion of the difficult relations between Mr. Benedito and Alberto. Mr. Benedito criticizes the behavior of both his son-in-law and his family, who usually speak loudly and use offensive words.

He states that, sometimes, he feels very sad, having difficulty to sleep and has been using alcohol for some time to feel better, but he says that he “is not a drunkard” and that he has never let anything go amiss (food, clothing) at home.

Ana observes that her father helps her every time it is necessary (clothes for the children, medication, cosmetics), so she was made responsible for the mother’s healthcare, seeing the situation as an “exchange”, or “mutual help”, but still, she is worried with her father’s health.

Such solidarity may be defined as a feeling awakened in the family due to the relationship of responsibility among people brought together by affective bonds, defining helping a member who experiences the process of treatment of a disease as a moral obligation⁽¹⁰⁾.

The following interventions were performed: highlighting Mr. Benedito’s willingness to remain by his family for all these years, even when facing the difficulties of his wife’s disease; explanation that his grief might stem from the suffering that he has gone through for years, orienting him about ways to reduce the damages from alcohol abuse, discuss the possibility of having him submitted to mental healthcare service, and, as arranged in the previous session, Ana was referred to a reference health center, after the end of the sessions.

In the fifth meeting, Mr. Benedito showed irritation when asked to receive mental healthcare attention, saying that he did not have “head problems”. Ana argued that that was not the case, being it simply taking care of the mind, just as they take care of the body’s health.

Since this was the last meeting, Ana said remarked that she found this kind of healthcare service a good idea, since she had the opportunity to have a better understanding of the mental disease and also to

understand and have more patience with her father’s mood swings.

In her opinion, we, “healthcare professionals”, were able to learn about the situation that she has at home. She felt comfortable enough not only to expose the problems that she has regarding her parents, but also to her other problems, such as the gynecological issue, and also to hope to get better since she is frequently seeing to the problem professional help. Her father said that it helped, because “talking is good”.

Ana says that she would like to talk more often to her father and, for him, the feeling is reciprocal. They both remember that they used to talk more often and share “a good laugh”, and they believe that this has decreased because of their daily tribulations.

The nursing interventions included the following actions: clarify the mental healthcare service and suggest that father and daughter arrange some time to meet and talk, such as at the end of their day.

DISCUSSION

The PSF’s operational guidelines highlight the focus on the family, inserted in its socio-cultural environment as the basic nucleus of assistance. It is of utmost importance to capture the multi-causality of the mental, physical and social health aggravators^(11, 12). Therefore, when the healthcare team faces a complaint in the family context, the perceptions extend beyond the individual focus and settle on the family.

While the family healthcare team was centered in the biological complaint, they did not acknowledge the need for interventions, since the senior was clinically stable. From the moment when we proposed to approach the family as a whole, under a systemic focus, it was possible to identify and care for the suffering of the family generated by this context.

By attending to the family under a systemic focus, it was possible to interact with them and to perform a detailed assessment of the family group. From there, in partnership with this family, several interventions were proposed to improve the quality of life of the family, so that they could also develop their own solutions to face adversities.

Therefore, one of the greatest potentials of the Family Healthcare Program resides in its capacity to offer support and strengthen the families under its responsibility.

FINAL CONSIDERATIONS

This study allowed us to highlight that it is important not only to politically determine that the family healthcare team should approach the family unit. It is necessary to have instruments that enable the professional to adopt

such an approach.

The systemic reference has been shown to be very useful when listening to the family group as a whole. Nursing has much to contribute to family healthcare and this research shows how nursing interventions can contribute to the improvement of the quality of life of the family unit.

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