Case Report

Relato de Caso

The collective construction of a guide for caregivers of bedridden patients: experience report

A construção coletiva de um guia para cuidadores de pacientes acamados: relato de experiência

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Keywords

Homebound persons
Family relations
Caregivers
Home care services
Guideline
Family health
Primary health care

ABSTRACT

This is a qualitative descriptive-exploratory study that adopts as data gathering method the participant observation of healthcare processes carried out by caregivers of bedridden patients from the coverage area of a Family Health Team of a Basic Health Unit (BHU) in São Paulo (SP), Brazil. The aim of this study was to report the construction of a guide for caregivers of bedridden patients and/or patients confined to the home. This guide was prepared based in a partnership among the Family Healthcare (FHT) and the speech-language pathologists and audiologists teams, and the caregivers of patients from the BHU. The guide was motivated by the construction of a common knowledge, with the aim to contribute with the creation of collaborative networks, apt to be places of discussion and exchange of knowledge, in order to optimize the ability of caregivers to early identify situations that require intervention. The networks also contributed to the valorization of caregivers' role; their knowledge on how to perform in daily living activities; overcoming of limitations; demonstration of actions aimed at the physical and mental well-being of the sick person; expansion of the capacity of ownership of processes of illnesses, autonomy and co-responsibility in healthcare. The guide was printed and delivered to FHT members, healthcare professionals and the community. The feedback was positive and, therefore, the guide was successful for the proposed objective.

Descritores

Acientes domiciliares
Relações familiares
Cuidadores
Serviços de assistência domiciliar
Guia
Saúde da Família
Atenção primária à saúde

RESUMO

Trata-se de estudo descritivo-exploratório de natureza qualitativa que adota como método de coleta de dados a observação-participante dos processos de cuidados à saúde realizados pelos cuidadores de pacientes acamados, pertencentes à área de abrangência de uma Equipe de Saúde da Família que atua em uma Unidade Básica de Saúde (UBS), localizada em São Paulo (SP). O objetivo deste estudo de caso foi o de relatar a construção do "Guia para cuidadores de pacientes acamados e/ou com restrição ao lar". Este guia foi elaborado a partir de uma parceria entre as Equipes de Saúde da Família (EqSF), fonoaudiólogos, e os cuidadores de pacientes usuários de uma UBS. O guia foi fundamentado pela construção de um saber comum, com o intuito de contribuir com a criação de redes colaborativas, que possam ser espaços de discussão e troca de saberes. Estas redes foram extremamente úteis na potencialização da capacidade dos cuidadores em identificar, precocemente, as situações que requerem intervenção. As redes também trabalharam com a valorização do papel do cuidador; seu saber quanto à forma de atuar nas atividades de vida diária; superação das limitações; demonstração de ações que visam o bem estar físico e psíquico do sujeito doente; ampliação da capacidade de apropriação dos processos de adoecimento, da autonomia e da co-responsabilidade no cuidado à saúde. Após a impressão do guia, o mesmo foi entregue as EqSF, aos profissionais de saúde e a comunidade. O feedback foi positivo e, sendo assim, conclui-se que o guia atingiu o objetivo proposto.

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Received: 5/20/2011

Accepted: 7/26/2011

Study conducted at the Speech-Language Pathology and Audiology Undergraduate Program of the School of Human and Health Sciences, Pontifícia Universidade Católica de São Paulo – PUC – São Paulo (SP), Brazil, and the Speech-Language Pathology and Audiology Undergraduate Program of the School of Medicine, Universidade de São Paulo – FMUSP – São Paulo (SP), Brazil.

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INTRODUCTION

This paper reports the construction of a "Guide for caregivers of bedridden patients and/or patients confined to the home", developed within the context of the Family Health Strategy by a collective effort among the Family Healthcare Team (FHT), speech-language pathologists and audiologists, and caregivers of patients from a Basic Health Unit in the city of São Paulo, Brazil.

The Family Health Strategy (FHS) inaugurates, among other things, the possibility of mapping the population in its territorial base, broadening the knowledge about life and health conditions of persons and social groups at social risk and vulnerability, as it is the case of bedridden patients and people with special needs(1). Before the FHS, in traditional assistance models, we couldn't effectively reach this population group, since the organization of health work focused only on the demands that arrived at health services, and not on the demands based on registration and diagnosis of the residents of the enrolled area(2).

The FHS supposes that the organization and planning of actions occur after close contact with the population and its conditions of life and access to health. This occur based on the mapping of the families of a particular area, of the responsibility for the construction of answers to the health problems of a specific territory, fighting social configurations that can lead to illness(3).

Hence, the possibilities of development of health attention strategies that deal with the technical and social dimensions present on the processes of healthcare are expanded. Without a doubt, the FHS has been important in the process of qualification and improvement of healthcare practices, since it allows a more effective approach to the patient and its social and familiar environment, enlarging his independence and social circulation(4).

Another important characteristic of the FHS is to provide the rescue of attachment, reception and co-responsibility values, implicating managers, professionals and users in humanized care processes(5). Based on this feature, there are more chances to produce work in health and to create strategies for care and resolution of human illness processes guided by the principle of active participation of patients and their caregivers/families in the definition of therapeutic horizons(6,7).

It is necessary to change the view of health professionals based on two basic principles that should guide any sanitary action: to know the human, and to count with the human. The first principle indicates that knowing the individual means getting to know him and, above all, understanding his believes, habits, roles and circumstances, and creating possibilities for efficient and permanent health actions. The second principle postulates that one cannot take care of someone else's health without taking care of himself. It is essential that the community can share the construction of the programs that are implemented, and not only to submit themselves to them(8).

Most Basic Health Units (BHU) offer, besides outpatient consultations, a series of programs and groups. However, it is common to see these actions being offered as part of pre-established plans, with rigid scripts and based only in epidemiological indicators. The groups in series or series of groups work out only one problem, the quantity of patients approached, but not the quality and continuity of care. If the offer is in group, it must be built upon group organization in order to be effective. This means that the group of professionals involved must be a team, that is, must collectively draw the devices to be implemented, evaluate its development, work as a group in its formation activities, analyze the received demands, elaborate its strategies and institutional policies along with other services and the community, and participate in the management and health policies(9,10).

This reflection, very pertinent and actual in the organization of health practices, demonstrates the challenges of building care strategies, not only based on epidemiological profiles, but also and fundamentally, on the listening of the health needs of subjects and social groups. Otherwise, one runs the risk of only reproducing pre-established models, silencing individuals and communities(2).

On the other side, the development of practices that escape these traps is not an easy task. We start from the idea that the care practices that consider the knowledge of the own subjects (that are going through some kind of pain) have greater chances to respond to health problems. With this purpose, a clinical position more favorable to listening, attachment and reception must be assumed(3).

One of the most precious aspects of health practices is in our ability to listen, to get to know the other. Such process is permeated and intertwined by the process of knowing the other's needs. One might think the production of work in health as networks of conversations, since health practices are meetings that operate, fundamentally, through the technique of conversation. Or yet, with the technique of dialogued reception(11,12).

The FHS, as the name suggest, for taking the family as a care unit, has the responsibility to act also on the quality of the attachment between caregivers and those in the position of "being taken care of". This perspective widens the participation of both, along with the health teams, in the definition of therapeutic projects. It is emphasized the importance to build health practices with the participation of all actors involved, which allows requalification of positions and actions through active partnerships with the population, creating new attachment models and constituting singular solutions to the demands that rise in these meetings(3,5).

Every health action, when carried out based on the shared responsibility and the joint construction of the intervention over the health-disease process, has greater chances to produce improvements in life conditions. One doesn't act only on the effort to ease the clinical-pathological symptoms, but also on the appropriation of knowledge and on the strengthening of social networks(5).

The family, as a significant element on this study, has a central role on the conduction of home care. In practice, it is the family that takes the direct responsibility for the care. It is the family that first identifies a problem, tries to translate and elaborate a reason for the situation, and makes decisions regarding the best way to conduct it.

However, when the need of care presents itself more permanently and with a condition in which no omissions are allowed, significant lifestyle and/or economic changes, besides the physical and emotional overload, are the consequences. Many times, the family is the only available resource for bedridden patients and/or patients confined to the home. Frequently, the realization of this function faces difficulties that can get even worse in families with unfavorable socio-economic conditions, which is the case in great part of the Brazilian population(13).

The present study has the aim to demonstrate the interrelationship and the collaboration among family health teams, Speech-Language Pathology and Audiology, and caregivers of bedridden patients in the construction of a common knowledge. The purpose is to contribute with the creation of knowledge networks, apt to be places of discussion and exchange of knowledge regarding the ways caregivers build their own benchmarks of care, usually marked by knowledge from common sense.

The main idea was to network this knowledge and contribute with the construction of a work in health that is based on the perspective of Collective Intelligence, broadening the autonomy of subjects in the management of their health problems. It is not the intention to convey the concept of autonomy as a way to close in on itself. Autonomy means listening to oneself, but also listening to others. This listening doesn't refer only to the specialist, but also to those going through a similar situation(14).

In the same direction, this study had the aim to contribute with the establishment of health policies and health programs directed towards the caregivers, caring for those who care. We had the aim to optimize the ability of caregivers to identify, with anticipation, situations that require intervention; to realize and value their knowledge regarding ways to intervene in daily life; to create and broaden community networks with the aim to contribute with overcoming the limitation of financial resources, time, and even competence to lead certain care processes; to recognize the value of home care in maintaining the patient's identity and psychological integrality; to value common sense knowledge and abilities in the process of care that address the physical and mental well-being of the sick individual; to broaden the ability to appropriate the processes of illness, autonomy and co-responsibility in health care.

The aim of this case report was to present the experience and the paths taken in the construction of a "Guide for caregivers of bedridden patients".

CLINICAL CASE PRESENTATION

This qualitative descriptive-exploratory study adopts as data gathering method the participant observation of health care processes carried out by bedridden patients and/or patients in situation of home restriction from the coverage area of a Family Health Team (FHT 3) of a Basic Health Unit (BHU) from São Paulo (SP), Brazil, in the Vila Nova Cachoeirinha neighborhood. The selection of the universe of subjects was in joint decision with the BHU. The FHT with greater number of registered adults in its area was selected as partner and research collaborator (Figure 1).

The criterion defined in the selection of the collaborator FHT was based on data from the Primary Care Information System (PCIS). These data indicate that, although children with disabilities have high degree of social vulnerability and, in some cases, live in situation of home restriction, the highest prevalence of bedridden patients is among adults, over 40 years of age, and elderly subjects (Figure 2).

The FHT 3 is composed by a doctor, a nurse, a nursing assistant, and six Community Agents. The field of the FHT 3 was divided into six microareas, which where responsibilities of each Community Health Agent (CHA) (Figure 3).

We opted to gather data from all the bedridden population of the FHT 3. The inclusion of 100% of the bedridden patients of a healthcare team allows greater conditions to map the microareas and use these data in future prevalence and incidence studies related to those types of health problems. The study was approved by the Research Ethics Committee of the Pontifícia Universidade Católica de São Paulo (PUC-SP) under process number 242/2007, and all participants signed the Free and Informed Consent Form.

Data gathering was structured based on four information sources:

- PCIS: survey of family registration data, with the purpose

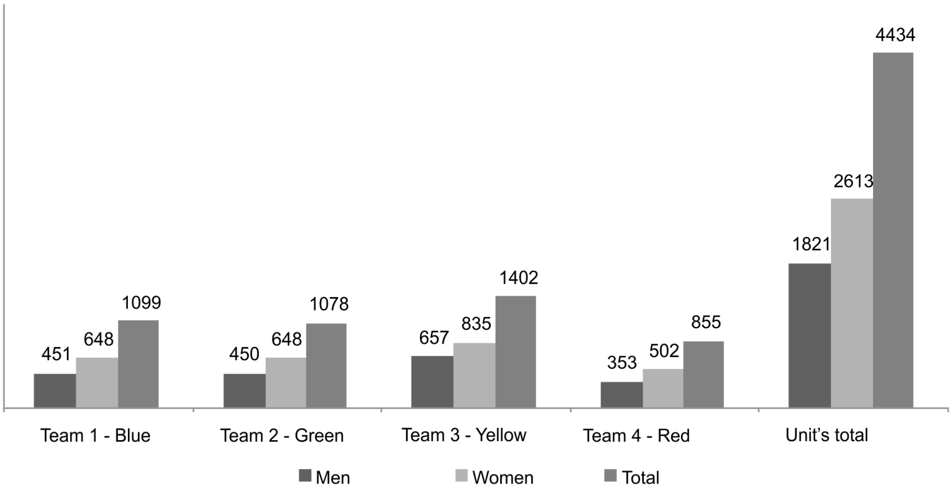

Figure 1. Number of adult persons over 40 years of age distributed by FHT

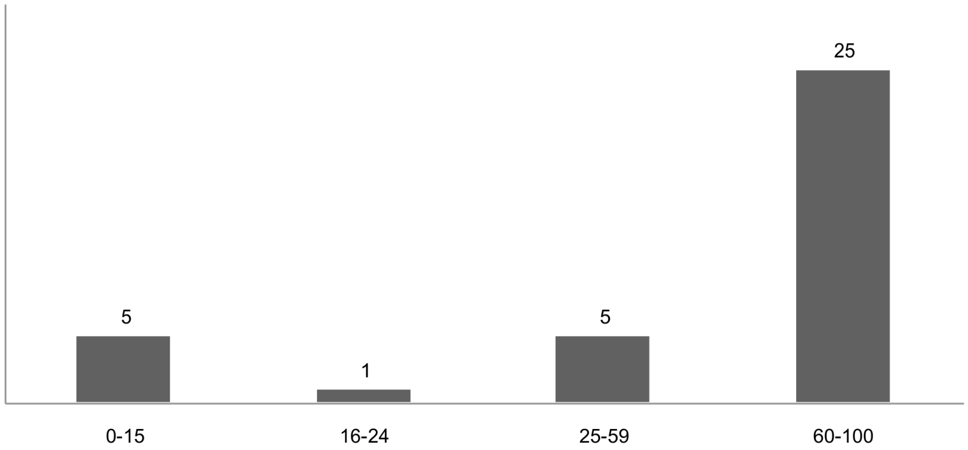

Figure 2. Distribution of the number of bedridden patients of the FHT 3 by age

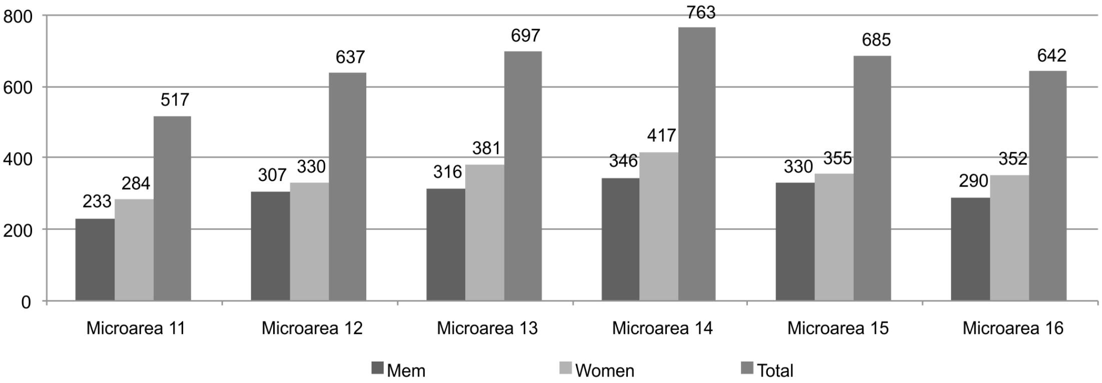

Figure 3. Number of registered persons divided by microareas

to characterize life and health conditions (schooling, treated water, garbage collection and disposal, sewer system, etc.).

- BHU records: survey of clinical history, main health problems, conduct and monitoring data from the health team, etc.
- Home visits: collection of data regarding the identification of the caregiver, family income, number of inhabitants and rooms in the house, hygiene conditions, physical adaptation of the environment, family organization, routine of daily chores, etc. (three to five visits for each family).
- Team meetings: accompaniment and registration of discussions of cases and creation of care strategies and therapeutic projects.

Registered data were analyzed and tabulated, with the aim to map life and health conditions and how the families conduct the care process. Along with the FHT, the purpose was to conduct Caregivers Groups and to elaborate the Caregiver Guide as support and discussion material about the caring task.

When the Caregivers Groups started, the analysis of data gathered from the PCIS, the records, the FHT and home visits was already well advanced, which significantly contributed for the structuring of the purpose of Caregivers Groups to be made based on these families' characteristics, difficulties and needs. The Caregivers Groups had the intent to promote an environment of trade of experiences and knowledge, as well as to verify their effect on the support and care for the caregiver. Five meetings were conducted, coordinated by the responsible researcher and the FHT.

The importance of the analysis of the data generated in the first stages of the research for the success of the Caregivers Groups and the elaboration of the Caregiver Guide is unquestionable. The quality and richness of the mapping and the analysis of the main operating modes, potentials and difficulties faced by caregivers are directly related to the possibility to optimize solidarity and collaborative networks based on the emergence of Collective Intelligence in groups and communities(14).

The analysis of our results was based on the crossing of data obtained in three different moments: PCIS data; data from records and home visits; data from the Caregivers Groups and the elaboration of the "Guide for caregivers of bedridden patients". Except for PCIS and records data, which were tabulated and registered in graphs and tables, all other data gathering moments were registered by the researchers through written reports.

The aim of these reports was to capture the relations, connections and flows established between caregivers/family members and bedridden patients. At this moment, we were facing new avenues of research, with less restrictive theoretical references and, therefore, with more opportunities to manifest the researcher's subjectivity(15) in the registration of qualitative data.

The registry of case discussions and the formulation of Caregivers Groups during team meetings, as well as the registry from the Caregivers Groups, demanded a research work that could capture the process "in action", since this is always relative to certain problematic, singular and contingent contexts that are traced as they are constituted(3). It is worth mentioning that the challenge in this moment of data collection and analysis was to deal with qualitative data as symbolic representation attributed to manifestations of an apparently imponderable event and its relationships with other events(15).

Centered on this methodological reference, the records of events were treated and generated the Caregivers Guide. Its content regards events, readings and representations that caregivers of bedridden patients and/or patients confined to the home could do from the meanings of their experience.

The production of healthcare technologies and the creation of new devices of the caregivers' own reception and care were accomplished only because a lot of effort was put into thorough data analysis and, fundamentally and mainly, because of the insertion of the researchers into the FHT work. Without this kind of accompaniment and partnership, the results wouldn't be the same, that is, it is emphasized the idea that every health action should be based on the co-responsibility and joint construction of the actors involved in these processes.

The major difficulty arose at the scheduling of the Caregivers Groups in the BHU, as we initially imagined. Stipulating common dates and times among caregivers seemed an impossible task. They had difficulties getting to the BHU, because they couldn't leave the bedridden subject alone for too long. Moreover, matching schedules for administration of drugs, feeding and other housework, and the times of physical space availability at the BHU seemed to derail the accomplishment of the Groups.

After a few tries, FHT, researchers, and caregivers decided to host the groups at the patients' houses. The houses chosen were the ones where the bedridden patients needed more intensive monitoring, and the other participants were divided according to proximity, in an attempt to facilitate the access of caregivers, since many of them are elderly and/or have limited mobility. Besides enabling the meetings, this strategy promoted the warming up and the creation of collaborative networks within the community itself, after the caregivers got to meet each other and found out they live very close to each other.

The dynamic of the groups was divided into four moments:

- First, each caregiver presented himself, told a little about his story, and how he became a caregiver (first meeting);
- Then, caregivers told a brief story about the bedridden patient under their care. At this moment, they began to identify and build common ground (second meeting);
- After that, based on the construction of a "community zone", we initiated a conversation circle, where a warm debate regarding their doubts, anguishes, and care strategies took place (second and third meetings);
- Last, a dynamic was carried out to symbolize what the group lived and to encourage new meetings promoted by themselves (fourth meeting).

The analysis of observations and registries of the four meetings was showed and discussed with the FHT, with the aims to share our findings and deepen the analysis of these data. The result of this process was an intense moment of trade of information and reflections able to collectively build alternatives to the problems of the caregivers. The most discussed themes were classified into ten myths of the caregivers, systematized on the Caregivers Guide:

- Myth #1: The caregiver doesn't get sick;
- Myth #2: The caregiver never fails;
- Myth #3: With little money there is no healthy eating;
- Myth #4: The caregiver doesn't need care;
- Myth #5: The caregiver cannot leave the house;
- Myth #6: The caregiver cannot sleep;
- Myth #7: The only friend of the caregiver is the bedridden patient;
- Myth #8: The caregiver doesn't have the right to grow old;
- Myth #9: To care is always a situation of sadness and grief;
- Myth #10: The caregiver has to take it all.

Initially 50 copies of the Guide were printed and handed to the members of the FHT 3 and the caregivers/families that participated on the study, to conduct a final revision. After their feedback, the material was handed at the Municipal Health Department, in order to conduct a graphic study and printing on a larger scale.

The construction of the Caregivers Guide represented a final effort of a whole study and research process. The idea was to leave a concrete product that could be useful for all healthcare professionals and communities. We emphasize, once again, that the greatest value of the Caregivers Guide is in how it was elaborated: a collective work that counted with the active participation of the whole Family Health Team, and also of the patients and their caregivers/family members. It's their voice on the Guide. The researchers' role was only to equate suffering situations and impasses faced in the daily life of these families, as well as to indicate some exit possibilities for these problems.

DISCUSSION

The physical and emotional health of different family members occupies a main role on the functioning of a family. As members are interconnected and dependent from each other, when any changes occur in the health of one of them, all are affected, and the whole unit is altered. That is, if the functioning of family influences the health and well-being of its members, it can be said that it affects the individual's health, and that the individual's health also affects the family(2).

The Caregivers Group had the aim to put in touch people with at least one thing in common: being caregivers of bedridden patients and/or patients confined to the home. Our hypothesis was that it would be extremely useful to activate a network of relationships that could work as a space for help and support for their problems: producing information and data that could serve to the production of knowledge for home attention; generating offers of humanized assistance that favor the exercise of autonomy and responsibility for one's own health. This was possible based on the development of actions along with families and the community for health promotion and the inclusion of persons with functional losses and dependent of their caregivers.

The strengthening of social networks of knowledge and the broadening of community participation, with the aim to contribute with overcoming these families' limitations, were also obtained.

The method used was based on the activation of conversation, of communication(11) not as a way to transmit or receive a message, but as a way to share meanings, a common context, a culture, a story, an experience. By circulating different experiences regarding the act of taking care of someone, this group device ends up broadening the reference universes and, hence, allows that each participant gets situated and orientated on everyday situations(14). In each of the Caregivers Groups (three groups with four meetings each), it was possible to observe some important dimensions of the condition of caring that frequently appeared in all meetings.

In the first meeting, when caregivers presented themselves, many realized they lived very close, that they had casual encounters on the streets, the market, or the pharmacy, and that it didn't mean they knew each other or the fact that they were facing the same situation. It was absolutely clear the link device that the stories of bedridden patients can cause. Constructed on this common ground, it was relatively easy, in the conversation circles in the second and third meetings, to put under discussion the difficulties of taking care of the other and of themselves.

During this process, more objectively on the second and third meetings, caregivers found themselves in the group, a place where they could talk about being a caregiver, clarify their doubts, anguishes, and feelings regarding this condition. A few questions raised by the group members showed the way they dealt with the situation of caring for a bedridden patient who, for being in a condition of extreme dependency, demands intensive and almost exclusive dedication. This aspect, in a certain way, is directly related to the almost impossibility to take care of themselves, since many of them put themselves in second plan and don't allow their own caring spaces. At the same time, it is evident their difficulty in sharing tasks or seeking for help.

The families' financial conditions were also discussed on the Caregivers Groups. Among other things, they related the difficulty of having healthy eating adequate to the low income.

Elderly caregivers presented difficulties to deal with their own aging, especially regarding their memory and mobility difficulties. They mentioned these problems as limiting to their caregiver function, which generate their fear of failure and risking the health of the bedridden family member. Many reported fear to sleep, believing that something could happen to the patient during their sleep.

Caregivers, in general, reported not to get out of the house much, and having difficulties maintaining a social life, getting away from the family, church, and friends. Many see in the bedridden patient their only friend. This was a very delicate aspect for the group, because it involves leaving their dependents at home, which generates guilt. They asked that the Guide had indications of psychological help, so that they could deal with these feelings.

The discussion of these information along with the FHT helped to deepen the analysis of the data gathered in these groups. This dynamic, besides promoting the idea that it was also needed to take care of those who care, tried to originate a set of information for caregivers/family members regarding alternative leisure spaces and accessible feeding orientations(2). Under this perspective, we decided to include in the Caregivers Guide a set of useful information that could be options for broadening of social circulation, such as units of SESC and CECCOs(10). Website links and telephone numbers of emergency and urgency numbers were also included in the guide, as well as websites with healthy eating tips, with low cost and maximum use.

In each group, the activities carried out in the fourth and last meeting, previously planned by the researchers and the team, also had the intention of building and/or activating collaborative networks. Besides playing the role of knowledge and strengthening device for collaborative networks, it was possible to observe, during group discussions, conflicts, needs, care strategies developed by caregivers and family member, circulation of affections, knowledge, etc(9). Hence, it was possible to capture valuable questions to think about care technologies and strategies based on what was experienced through the direct contact with these families, which could be systematized in the Caregivers Guide.

FINAL CONSIDERATIONS

The present study confirms the possibility to: develop actions along with families and the community for health promotion and inclusion of persons with functional losses and dependence, and their caregivers; develop health programs aimed at home care, not only to the bedridden patients and/or patients confined to the home, but also to their caregivers; to strengthen the collaborative networks of knowledge and broaden the community participation with the purpose to contribute for the overcoming of limitations of financial resources, time, and even competence to conduct certain care processes.

The printed finalized version of the Caregivers Guide was well received by the Family Health Teams and by the caregivers/family members of the bedridden patients. The feedback from the community was positive and, therefore, the Guide reached the purposed goal. Finally, we conclude that there is need for further qualitative researches in the field of Public Health and in the improvement of healthcare technologies that might involve the community with their own problems, improving the quality of life of individuals and social groups.

ACKNOWLEDGEMENTS

We thank the National Council of Technological and Scientific Development (CNPq), for the research grant (process # 07/706).

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