

## SWEDISH ADVANCED HOME CARE: ORGANIZATIONAL STRUCTURE AND IMPLICATIONS OF ADOPTING THIS CARE MODEL IN BRAZILIAN HEALTH CARE SYSTEM

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*The purpose of this paper was to describe the organization of the Advanced Home Care Program provided in a region of Sweden and to discuss some benefits and implications of this model adoption in Brazilian settings. Data triangulation as interview, observation and questionnaire was used. Thirty two professionals participated in this study. The organizational structure, working method, home visits, and related health resources were described. The investigated model presented both clear effectiveness and versatility; therefore feasible to be adopted in Brazilian settings improving their population health care. Doubtless, the improvement of life quality and security are the best benefits this model of care can provide.*

DESCRIPTORS: home care services; delivery of health care

## EL MODELO SUECO DE SERVICIOS DE ATENCIÓN A DOMICILIO PROVISTO POR HOSPITAL: ORGANIZACIÓN E IMPLICACIONES DE LA ADOCIÓN DESTA TIPO DE ASISTENCIA EN EL SERVICIO BRASILEÑO DE SALUD

*Este artículo tiene como objetivo describir la organización del programa de atención médica domiciliar avanzada en una región de Suecia y discutir los beneficios e implicaciones que pueden resultar de adoptar este modelo en Brasil. Como enfoque metodológico se utilizó la triangulación de datos combinando entrevista, observación y encuesta. Integraron el estudio 32 miembros del equipo profesional. Se describieron la estructura organizacional, el método de trabajo, las visitas domiciliarias y los recursos de salud implicados en la atención. El modelo investigado presenta evidencias de eficiencia y efectividad y se muestra versátil para ser adaptado a Brasil para atender a las necesidades de la salud de la población. Sin duda, la mejora de la calidad de vida y de la seguridad son beneficios sociales de grande relevancia que emergen de este tipo de atención.*

DESCRIPTORES: servicios de atención de salud a domicilio; prestación de atención de salud

## O MODELO SUECO DE HOME CARE AVANÇADO: ORGANIZAÇÃO E IMPLICAÇÕES DA ADOÇÃO DESTA MODALIDADE DE CUIDADO PELO SERVIÇO DE SAÚDE BRASILEIRO

*Este artigo descreve a organização do programa de "home care" avançado em uma região da Suécia e discute os benefícios e implicações que podem resultar da adoção deste modelo pelo Brasil. Como enfoque metodológico foi utilizada a triangulação de dados combinando entrevista, observação e questionário. Integraram o estudo 32 membros da equipe profissional. A estrutura organizacional, o método de trabalho, as visitas domiciliares e os recursos de saúde envolvidos na assistência foram descritos. O modelo investigado apresenta evidências de eficiência e efetividade e mostra-se versátil para ser adaptado ao Brasil para atender as necessidades de saúde da população. Sem dúvida, a melhoria da qualidade de vida e segurança são benefícios sociais de grande relevância que emergem desta modalidade de cuidado.*

DESCRITORES: serviços de assistência domiciliar; prestação de cuidados de saúde

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## INTRODUCTION

**H**ome care has been expanding rapidly in developed countries, due in part to the increasing number of elderly people and people with chronic illness consuming this service and in part to escalating health care costs, mainly in the hospital sector, and a consequent decreased emphasis on institutional care. The availability of suitable equipment for home care and the recognition of the importance of allowing consumers to choose have also been mentioned as a factor of great importance<sup>(1)</sup>. Terms such as advanced home health care, hospital-based home care and hospital at home have been used to refer to the delivery of specialized, complex care (with the use of high-technology equipment) and rehabilitation services at the patient's own home to support early discharge from acute hospital care and to prevent hospital admissions<sup>(2)</sup>.

In Sweden, home care service has a long tradition and was developed many years ago with the support of the authorities to replace institutional care<sup>(3)</sup>. In 1988 advanced home care was considered the most rapidly growing medical technology in health care. The two main causes were the need to reduce costs in the public sector at the end of the 1980s and greater demand for this type of care. The cost containment trend was due mainly to the higher proportion of people over 80 years in the Swedish population<sup>(4)</sup>.

Health care in Brazil is still strongly institutionally based. Most clients are elderly patients with chronic diseases requiring long-term institutional treatment<sup>(5)</sup> that constitutes a great burden on the hospital budget, its health assistance and the quality of the care provided. The Brazilian population is undergoing demographic transition, with an increasing population of older people. Forecasts suggest that in 2030 Brazil will be among the 10 countries in the world with the highest number of elderly people<sup>(6)</sup>. Although Brazil can not be considered as a poor country, in terms of resources, there is a high level of poverty due to the inequality in income distribution and in the opportunities of economic and social inclusion<sup>(7)</sup>. Because of that the access of the population in this lower strata to the health system is hindered. In the light of this, alternative forms of care are particularly important to meet the increasing need for health services.

The scarcity of financial resources and the high cost of the hospital assistance in the recent years have led to some changes in Brazilian medical care. The trend

is shifting towards deinstitutionalization and an expansion of the number of out-patients. There is increasing pressure to reduce the hospital stay and discharge patients earlier. However, it has not taken into account if the patients and their families are ready to continue the care at home. A study concerning surgical patients' discharge emphasized this gap between the hospital and the patients' home and pointed up the difficulties found by the families in the home environment such as: the lack of knowledge about how to manage either the patient or the disease as also that they were not given enough support from the institution<sup>(8)</sup>. Moreover, the search for alternative means of providing care outside the hospital setting reflects in some way the worldwide trend towards home health care.

Nowadays the Brazilian experience and publications concerning home care service are still in their initial stages. Therefore, the knowledge of the system in countries where home health care services have been developed over some decades can contribute greatly to the construction of a Brazilian model for organizing home care services.

## AIMS

The purpose of the present study was twofold: (1) to describe the organizational structure of hospital-based home care – HBHC (or Advanced Home Care) provided in a region of Sweden; and (2) to discuss the benefits and implications that might arise from the implementation of this model for the Brazilian health care system.

## METHODS AND DESIGN

A triangulation approach to the data collection according to Polit e Hungler<sup>(9)</sup> was used in order to describe the structure and organization of the service provided (HBHC) and to explore its working method. Data triangulation was achieved by the combination of three sources of information: 1- a personal semi-structured interview with the head of the department and head nurses of the HBHC unit; 2- non-participant observations of nurses' activities during the home visits; and 3- a questionnaire for members of the nursing and multidisciplinary teams. The project was undertaken in a city in the county of Ostergotland, Sweden, and located at a hospital-based

home care unit where home care activities are provided. Approval was granted by the Regional Research Ethics Committee.

The HBHC's senior physician and head nurse, 22 members of the nursing staff (19 nurses and 3 assistant nurses) and 10 members of the multidisciplinary team (2 physicians, 3 physiotherapists, 3 occupational therapists, a dietician and a social worker) who worked in advanced home care, took part in the study. Only the professionals who gave their informed consent participated in the investigation.

One of the researchers (MGP) accompanied the HBHC's nursing team (Acute Care, Palliative Care and Home Rehabilitation) in 25 home visits during three months. For this investigation two previously tested instruments were used: the researcher's observation guide (instrument 1) and a questionnaire (instrument 2). Instrument 1 guided the researcher's observation when following up the home visits together with the nursing staff. This form was designed around topics concerning personal characteristics of the patients such as age and sex, the reason for the visit and its length, actions developed by the staff, material supplies and technological resources. Instrument 2 was a questionnaire with open-ended questions for the nursing and multidisciplinary teams. It comprised information regarding personal and professional characteristics as well as information concerning organizational aspects of the service (working method, human and physical resources, documentation, and assistance model).

After the questionnaire had been designed, a pilot study was carried out with health professionals performing at another unit of the HBHC, and revisions were made. Eighty questionnaires were distributed to all nursing staff (n=57) and other health professionals (n=23) working at the HBHC unit, including the day and night shifts as follows: 36 nurses, 21 assistant nurses, 7 physicians, 7 physiotherapists, 7 occupational therapists, a dietician and a social worker. The overall response rate for the questionnaires was 40% (32). It represented 22 (38.6%) of the nursing staff and 10 (43.5%) of the multidisciplinary team. After the data had been gathered, a preliminary written version was sent to the HBHC's head nurse and to a registered nurse with long experience in working with advanced home care to validate the findings. The statistical package used for processing the descriptive data was SPSS, version 10.

## RESULTS

### Interview

Hospital-based home care activities in the city studied are conducted by an independent clinic connected to the geriatric ward at the university hospital. The clinic is open 24 hours a day, 7 days a week and is managed by a senior physician and a head nurse. Its philosophy is to meet the physical, emotional, social and existential needs of the patients through interdisciplinary team work in a holistic approach that focuses on quality of life.

HBHC provides a wide variety of health care and social services to terminally and chronically ill, recovering or disabled people. These encompass medical and nursing care, therapeutic treatment, assistance with the activities of daily living (ADL), nutritional care, counseling, spiritual and religious support in bereavement, laboratory service, pharmaceuticals, medical equipment and supplies. The program is divided into three branches for adult patients: palliative care (at the patient's home and in an 8-bed palliative care unit in the clinic), acute care and rehabilitation (at home and for outpatients).

The home care personnel are a multiprofessional team. The staff employed for the palliative and acute care encompasses 1 head of the unit, 2 administrative nurses, 3 secretaries, 34 nurses, 21 assistant nurses, 6 physicians, and 1 dietician. The rehabilitation care staff is made up of 1 unit head, 9 physiotherapists, 9 occupational therapists, 2 nurses, 2 assistant nurses, 2 speech therapists, 1 social worker and 1 secretary. When recruiting nursing staff for the HBHC units, there are no requirements concerning a minimum number of years of experience or any specific qualification in palliative care since most nurses have received training in pain management at the university nursing school. Physicians also receive training in such matters at the university.

The clinic uses a quality control of pain and pain relief. The next of kin are also invited to visit after the patient's death to evaluate the appropriateness of the pain control and care provided, to assess how well the members of the family have accepted the patient's death. Complaints can be addressed to other professionals in the team or directly to the head nurse of the unit or even to the senior physician of all three branches of HBHC. A patient ombudsman can also be consulted.

HBHC's statistical data show that 859 patients

were enrolled into the program in 2002. A total of 28 744 home visits were provided by the multiprofessional team. Of these, 5% were carried out by physicians, 46.2% by nurses, 25.1% by assistant nurses, 11.9% by physiotherapist, 10.3% by the occupational therapist, 0.5% by the speech therapist, 0.6% by the social worker and 0.4% by the dietician. The monthly average of visits was 2 396. The average periods of staying in the program were the following: 23 days (acute care), 42 days (home rehabilitation), and 95 days (palliative care). For the development of its activities the HBHC organization investigated is allocated resources from the county council from a fixed budget. The annual budget (2002) was SEK 26 million or about 2.8 million U.S. dollars (1 US dollar = 8.6 Swedish krona). Personnel costs amounted to SEK 20.5 million (2.2 million dollars), which represents 78.8% of the total. The remaining refers to material and equipment, infrastructure, and administrative activities.

#### Observation

During the observation period, 23 patients were attended at home (two patients received more than one visit during the same day). The patients ranged in age from 22 to 91 years (mean 63.7, SD= 16.6). The majority of them (n=15) were between 50 and 69 years of age and 16 were women. Most part of the patients suffered from malignant diseases, mainly gastrointestinal and lung cancers. Cardiovascular diseases also represented a great part of the diagnosis (n=5). Twenty visits were planned, and five were acute. The reasons for the planned visits included treatment requirements such as administration of drugs (n=9), dressings (n=3), and collection of blood samples for laboratory analysis (n=3). The acute situations were mainly related to pain control.

The length of the visits varied from 10 minutes to about 1 hour and 45 minutes, with a mean of 33.2 minutes (SD =25.5). Most of them were performed by the registered nurse (n=14), and by the registered nurse and physician (n=6). Initial evaluation visits, the need to adjust the medical prescription or even changes in the patient's overall status required the physician's presence. Twenty-three of the visits took place at the patient's own home, and in only two situations were the patients attended in a nursing home and in sheltered accommodation. Whenever the personnel were out visiting patients, they were connected to the HBHC unit via a mobile telephone.

The basic material for everyday home visits was carried in the nurse's and assistant nurse's backpacks, which contained a small supply of medicines for normal and acute situations, and commonly used supplies items. HBHC also maintains a store of equipment and pharmaceuticals for urgent situations. Daily, prior to the home visits material resources are assessed, and at the end of the shift, material that has been used is replaced by the nursing staff.

Each day the senior physician meets the multidisciplinary team to analyze new referrals and decide whether the patient fulfills the general criteria for admission into the hospital-based home care program. Criteria include: the need of medical care; whether the patient's home is within a driving distance of 30 minutes from the HBHC base; the desire and possibility to stay at home during the illness; the social and practical situation in the home setting; next of kin's approval and desire for this means of assistance. Once the patient is accepted into the program the physician and the nurse in charge make a schedule of planned visits based on the patient's estimated care needs. Periodically this list is reviewed, and extra visits can be performed as required. The patients are re-evaluated at weekly team meetings concerning their medical and nursing conditions, and adjustments are made when necessary. Each branch of HBHC (palliative and acute care) has a designated physician and nurse team leader. There are no supervisors. All the professionals involved in the care operate independently and autonomously in making their decisions.

#### Questionnaire

Despite the low number of questionnaires that were returned to the researcher (n=32) and the number of questions in which the participants did not supply data, it was possible to build up an overall picture of the advanced home care program in the city. The low response rate (40%) could possibly be explained by staff difficulty in describing the activities performed or apprehension about making critical remarks about the program.

The mean age of staff participating in this study was 44.4±10.1 years old. Their mean professional experience was 17.1±10.6 years, with an average of 7.6±6.6 years spent at HBHC. The female gender was predominant. More than half of the nurses and half of the multidisciplinary team were not specialists. The following specialties were



represented: medical and surgical, primary care, operation room and intensive care (nurses); geriatrics and internal medicine (physicians) and palliative care (social worker).

To elicit the home care support team's perceptions about the activities performed, questions related to qualification, communication process, the quality of care, care planning, documentation and favorable and unfavorable aspects of the home care program were asked. Many individuals on the staff mentioned the following key skills: competence, communication skills, perception and sensitivity to the patient's needs, flexibility, collaboration, and teamwork. In response to the question concerning the way the communication process among staff members and patients/next of kin was perceived, the majority (n=23) reported good quality of communication with some of them (n=9) reporting very good communication. The staff emphasized close contact with the patients and next of kin through an open and professional dialog that resulted from being sensitive to their needs. The participants evaluated the quality of care provided by HBHC's care teams in the city as good (n=4), very good (n=19) and excellent (n=9). The staff competence and availability, teamwork, their ability to meet patient's needs, a holistic vision of caring, pain relief, adequate technical aid and the effective service organization were considered as essential elements of the quality of the service provided.

Respondents (n=32) were asked to make comments on the appropriateness of the care planning used at the service to identify the patient's needs. Of those who answered most (n=25) considered the care plan appropriate, and only two considered it inappropriate. Those who considered it appropriate said that it provides good insight into the patient's needs and the goals of the treatment for all co-workers as the patient and his or her family members are included in the development of the plan. Moreover; the professional involved in making the care plan is always the same and that the plan is updated. No justification was given by those who considered the care plan inappropriate. Concerning the management of information, almost all members of the staff (n=28) reported that the home care record contains all the necessary patient data for the team's evaluation since the relevant aspects of the care are registered by each category of professional. Sometimes the documentation is a little extensive, presenting duplicate information or even incorrectly located data. The possibility of receiving qualified and competent professional care at home, continuity and self planned

care, 24 h availability, security, and collaboration among all the personnel categories were referred to as favorable aspects of the HBHC Program. Improving the collaboration between the HBHC and primary health care could enhance the organization's performance.

## DISCUSSION

Being cared for in the home setting: benefits to the patients and impact on the informal caregiver

Home and hospital are environments contrasted by cultural aspects. In contrast to the hospital, which is a public institution and represents the world of medicine centered on biological conditions, the home is a private setting representing the world of "normal life" where the center is the personal history<sup>(10)</sup>. Caring at home involves understanding and respect for the patient's personal characteristics and values. In Sweden, care needs are recognized as individual and unique to the patients and the right to make decisions concerning the place and nature of care is assured. There is also a preference for receiving care at home, mainly during the final stage of their lives<sup>(11)</sup>.

The Hospital-Based Home Care program offers patients in need of specialized medical care and technical nursing procedures who wish to remain at home, the possibility to receive palliative and acute care and rehabilitation from a multidisciplinary working team. The easy accessibility to the program creates a feeling of safety for both patient and next of kin since they can receive 24-hour support for home visits (planned or in emergency situations) and advice within 30 minutes after a phone call. For the patient in need of more extensive medical treatment there is the possibility of using hospital facilities at any time. The frequency and the length of the home visits as well as the length of time the patient is enrolled into the program are not limited. Care is planned with the active participation of the patient and next of kin to meet the patient's wishes. Security is also achieved through qualified professional assistance, continuity of the care with the same team member and free of charge delivery (co-payments), as well as installation and use of equipment, technical devices, consumables and pharmaceuticals at the patient's home.

The major contribution of the program is to help

patients maximize quality of life even in face of a terminal illness by providing continuous symptom control, effective pain management, psychosocial and spiritual support, and bereavement care. A next of kin satisfaction survey concerning care provided by HBHC<sup>(12)</sup> revealed a highly positive attitude towards this means of care.

One important criterion for admission into the hospital-based home care program is the next of kin's approval and request for this means of assistance, since family members take an active part in the care at home. The caregiving role may create a high level of strain for the informal caregiver (caregiver burden), which may cause psychological, social, physical and economic problems<sup>(13)</sup>. In the last decade informal caregivers have been receiving more attention in Sweden. Studies associated with the experience of giving care and the caregiver's burden development have been extensively documented in the country, emphasizing the importance of supporting programs to promote relief and raise caregiver's coping abilities<sup>(14)</sup>. Moreover, it has been suggested that the government should offer support programs to the next of kin. Consequently, the Swedish welfare system has offered two different types of support: a home-care subsidy and municipality programs. The first constitutes economic support for the individuals who want to care for a severely ill family member or even a friend staying away from their work. This benefit covers a period of about eight weeks<sup>(4)</sup>. Specific support programs for informal caregivers have been provided by the majority of Swedish municipalities. Examining the Swedish experience of caregivers' burden it is possible to understand the importance of the Brazilian public sector in supporting informal caregivers at home in order to increase their coping abilities. Otherwise, the caregivers will not be able to provide care, and the consequences to the care-receiver, family and health system can be negative.

Health care providers: the core of the HBHC organization

The HBHC's organizational design and dynamics favor a high degree of decentralization and autonomy. The home care teams work in an independent way what demands knowledge, skills, and the ability to make decisions and improvise. However, they are not on their own. If a problem arises during the visits, the team members can get immediate support from the unit via mobile phone. It is also possible to contact the physician

in case of acute deterioration of the patient's health or in other unexpected situations. The members are mutually dependent and supportive, and operate together with a common, agreed goal. The multidisciplinary team work uses a holistic approach that focuses on meeting the patient's individual care needs.

Although the specific tasks to be carried out by each member of the multidisciplinary team at HBHC are not formally established and might overlap slightly, conflicts among different professionals are almost non-existent. In Sweden, registered nurses and assistant nurses are educated for performing distinct roles. The administration of intravenous drugs and other specialized procedures, such as management of different types of catheters are performed only by registered nurses. Assistant nurses are not allowed to administer medications except for subcutaneous medication like insulin, on delegation. In Brazil, the duties of registered nurses and assistant nurses consist of a series of overlapping activities, which sometimes causes difficulties. The same situation occurs between nursing staff and other members of the multidisciplinary team. Therefore, a written job definition for each home care professional category is extremely important.

Registered nurses constitute the largest professional category in the HBHC staff. There is also a preference for nurses instead of assistant nurses. The importance given to nurses in Sweden can be observed in the high ratio of nurses compared with other countries in the European Union<sup>(15)</sup>. According to the HBHC's statistical data for 2002, the nurses were the professionals who provided most of the home visits - 46.2%. The nursing team was responsible for 71.5% of all the visits provided.

The advanced home care unit studied does not require previous professional experience when recruiting personnel or that applicants should have any specific qualifications in palliative care. However, the program offers initial training and in-service education to improve staff competence. In Brazil, a minimum number of required years of experience for the health professionals before starting working with advanced home care would be recommended. Courses in palliative care and related subjects must be introduced as content in the basic medical and nursing education program or in some independent training courses since this specialty are still incipient in the country.

## Societal impact of implementing this model on the Brazilian health system

One aspect to be considered related to the implementation of the HBHC model investigated in Brazil is that the service needs to be a part of the health system - as in Sweden - to guarantee equal access to all citizens independently of economic resources. The Brazilian public and decentralized health system<sup>(16)</sup> established in 1988 in theory should have improved the population's universal access to the healthcare services. However, nowadays is still possible to observe inequalities in the consumption of such services. The inequalities in health reflect in some way the social inequalities. Studies about the relationship between social inequality and health in Brazil has shown that those individuals in the lowest income distribution deciles have greater need for medical care, less access to health insurance, and lower consumption of health services<sup>(17)</sup>.

To expand the perspectives of access to the health system of those traditionally excluded, it was implemented, in 1994, The Family Health Program, as a model aiming at health prevention and promotion to individuals and its family through a multidisciplinary approach<sup>(18)</sup>. Although this Program has provided home care visits, they are most related to health promotion activities. Those in need of specialized, complex care (with the use of high-technology equipment) and rehabilitation services at home since they are discharged earlier, still do not have any support from the Brazilian public health service.

In some extent, the Brazilian experience with home care has been even incipient. Some programs have been implemented by private, public and university hospitals, but most part of the activity has been provided by private health insurance companies excluding great part of the population in the lower social strata. Investigation of some adequate model has been performed since many of these programs are structured differently according to the clientele. Since there is not either an official regulation for Brazilian home care or rules to support the professionals work the development of health policies is mostly required as regard as advanced home care programs.

Furthermore, there are some aspects of this issue that need to be cleared up. The patient and next of kin must have a free adherence to the program. They might choose between being treated via conventional hospitalization or at home. In this way, home care is an **option** and not an **imposition**. It would be dangerous if

the government authorities transferred their responsibility for caring to the informal caregiver to reduce the health costs. A WHO report<sup>(19)</sup> recommended a balance between family and public responsibility to avoid informal caregiver being burdened and left to their own devices. Due to the socio-economic and socio-cultural differences among people in Brazil it becomes essential that the government sector develop policies to create the required environment for a sustainable and effective home care. It encompasses the provision of supplies, equipment and financial support to compensate for the informal caregiver's loss of earnings in line with conditions offered in Swedish welfare. However, to make a conscious option for this means of care, potential informal caregivers need receive the fullest possible information about the extent of their participation in providing the care and the support they can expect from the health professionals<sup>(1,19)</sup>. Teaching the families to provide care in the home environment is equally important to increase their quality of life as well as the education for health professionals to insure that the patients' needs are met and the co-ordination of the care delivered.

Another aspect of concern within advanced home care is the cost-effectiveness of operating such a program instead of using institutionalized assistance. In Sweden, this is very controversial. There is a lack of surveys concerning health economy on advanced home care and home rehabilitation<sup>(20)</sup>. Some cost surveys have been performed since the beginning of the HBHC<sup>(21)</sup>. However, they have been carried out based on specific patient groups, including different main outcome measures and using distinct methodological approaches. Some of them indicate home care as a less expensive alternative to hospital care<sup>(21-22)</sup>; others equally expensive<sup>(11)</sup> and yet others as more expensive<sup>(20)</sup>. Nowadays, it is considered that cost evaluations of home care programs which do not take informal care costs into account are often underestimated since the informal caregivers lose paid work and leisure time with the caring activity which could be performed by a health professional<sup>(20)</sup>. Although all the above mentioned costs studies were based on Swedish data, they are probably applicable to Brazil.

## CONCLUSIONS

It is not easy to create a basis for comparative analysis between the Swedish and the Brazilian health systems since these countries differ largely in economic

and social conditions, culture and tradition. However, when examining the experience of developed countries in structuring their health services and in searching for solutions much can be learned by developing countries such as Brazil. Sweden has a long tradition of specialized services in home care. The hospital-based home care model investigated has shown evidence of efficiency and seems sufficiently versatile to be adapted to meet the Brazilian population's health needs.

However, moving from institutional care to home-based care can not be seen from a restricted perspective of cost containment. The quality of life improvement and safety are social benefits of great concern which result from this means of care. The development and discussion of Brazilian policy for home care programs and the government's role in funding the universal application of these services are of vital importance. Equally essential is the need to structure the activities performed to create an organizational model that is suitable for the Brazilian health care. The implications for health care providers and informal caregivers require further research.

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