

# Visiting hospices in Germany and United Kingdom from the perspective of palliative care

*Visitando hospices na Alemanha e no Reino Unido na perspectiva dos cuidados paliativos*

*Visitando hospices en Alemania y Reino Unido en la perspectiva de los cuidados paliativos*

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## ABSTRACT

**Objective:** Report on visits in hospices located in Osnabrück/Germany and the Saint Christopher's Hospice in London/United Kingdom; and present a discussion about the care mode. **Methods:** Experience report based on a post-doctoral research period in Germany between November 2013 and October 2014, funded by the CAPES Foundation (Coordination for the Improvement of Higher Education Personnel). **Results:** The structure, operation mode of the institutions and the main labor force were discussed, especially the nursing staff and volunteers' participation, the main care activities and challenges. These issues were very similar at the hospices, highlighting the hospice responsible for spreading this movement worldwide. **Conclusion:** The hospice may be the place of death, but it provides a pleasant environment that preserves the person's individuality and autonomy. It relies on the participation of volunteers, dissemination of its idea and training programs, which ensure the strengthening of this movement.

**Keywords:** Palliative care; International educational exchange; Nursing.

## RESUMO

**Objetivos:** Relatar a experiência de visitas realizadas em hospices situados em Osnabrück/Alemanha e, em Londres/Reino Unido, no Saint Christopher's Hospice; e apresentar uma discussão acerca, deste modo, de cuidar. **Métodos:** Trata-se de um relato de experiência, a partir da realização do estágio pós-doutoral na Alemanha, de novembro de 2013 a outubro de 2014, com apoio da fundação Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - CAPES. **Resultados:** Relatou-se a estrutura física; modo de funcionamento das instituições; principal força de trabalho, com destaque para a equipe de enfermagem e participação de voluntários; principais atividades assistenciais e desafios. Tais questões nos hospices foram bastante similares, com destaque dado ao hospice responsável pela disseminação deste movimento mundialmente. **Conclusão:** O hospice pode ser o local do óbito, sendo ambiente agradável, que preserva a individualidade e a autonomia da pessoa, conta com participação de voluntários e com programas de divulgação e treinamento, para fortalecimento do movimento.

**Palavras-chave:** Cuidados paliativos; Intercâmbio educacional internacional; Enfermagem.

## RESUMEN

**Objetivo:** Relatar la experiencia de visitas realizadas a hospices situados en Osnabrück/Alemania y Londres/Reino Unido y presentar una discusión acerca de este modelo de atención. **Métodos:** Relato de experiencia a partir de la formación post-doctoral en Alemania (noviembre 2013 a octubre 2014), con el apoyo de la Fundación CAPES (*Coordenação de Aperfeiçoamento de Pessoal de Nível Superior*). **Resultados:** Fue reportada la estructura física; el modelo de funcionamiento de las instituciones; la principal fuerza de trabajo, destacando el equipo de enfermería y la participación de voluntarios; actividades de asistencia; desafíos. Tales cuestiones en los hospices fueron muy similares, con énfasis al hospice responsable por la difusión mundial de este movimiento. **Conclusión:** El hospice puede ser el lugar del óbito o un ambiente agradable, que preserva la individualidad y la autonomía de la persona, tiene participación de voluntarios y programas para la difusión y capacitación que garantiza el fortalecimiento del movimiento.

**Palabras-clave:** Cuidados paliativos; Intercambio educacional internacional; Enfermería.

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## INTRODUCTION

Brazil, a developing country, faces many challenges, related to the limited supply of specialized services and the population's great demand for end-of-life care. This is due to a recent change in the epidemiological profile, highlighting the high incidence of new cancer cases and the increased number of elderly people. According to data from the *Instituto Nacional de Câncer* (INCA), for 2014, also valid for 2015, approximately 576 thousand new cancer cases are estimated, underlining the magnitude of the problem in that country<sup>1</sup>.

The problems of the current Brazilian health system with regard to access difficulties to health services, resulting in the late diagnosis of the disease, to the deficits in professional education, as well as to the long waiting time between the diagnosis and the start of treatment, are factors that contribute to the high morbidity and mortality rate due to cancer.

In all management spheres, this scenario has driven the allocation of resources with a view to positively influencing the statistics. Nevertheless, it should be alerted that investments in end-of-life care are fundamental, not only aiming for disease control, active and healthy aging or promotion and prevention actions in this context<sup>2</sup>, but also to offer quality of life to these people, in view of the possibility/reality of death.

Hence, we agree with the fact that end-of-life care represents a need and not an alternative. It can be considered a "biopolitical device invented in defense of society", especially in poor and economically developing countries<sup>3,5,18</sup>.

Different palliative care modalities exist, which are: hospitalization (palliative care wards), home care, outpatient care, emergency care service and hospice.

The word hospice translated the Latin word *hospitium*, which means "accommodation, hospitality" and translates a feeling of welcoming. This movement involves a primary concept of care, which does not refer to an actual physical structure, but to the philosophy of hospice care. This philosophy disseminates the idea that plenty can be done to help people suffering from an incurable and progressing disease. In the literature, besides the meaning based on the origin of the word, the term hospice care joins different definitions. Nevertheless, all of these cover the essence of care for people with advanced and incurable diseases. In addition, the majority is related to: symptom control; quality of life; participation of volunteers; community-based care programs; care in mourning phase; family care; and interdisciplinary work<sup>4</sup>.

It is highlighted that the palliative care concept originated in the hospice movement, idealized by the nurse, physician and social worker Cicely Saunders, who disseminated the care philosophy around the world, based on effective pain control, and care for the psychological, social and spiritual dimensions of people suffering from an advanced disease<sup>5,6</sup>.

Hence, to value the initiative and the importance of hospices in the palliative care context, this study aimed to report on the experience of visits made to hospices located in Osnabrück, Germany and London, United Kingdom, as well as to discuss this care mode based on another form of reasoning.

It is highlighted that care based on the hospice model is recent in Brazil and that the palliative care programs in urban areas currently represent isolated initiatives without networking<sup>7</sup>. Nevertheless, in view of its renown value in care for human beings who are dying and its relevance as an intelligent and fundamental strategy, this movement should be powered in the country by different means, including research.

## METHOD

Descriptive experience report of the visits made to two European hospices in March 2014, one in Osnabrück (Osnabrücker Hospiz), Germany and the other in London (Saint Christopher's Hospice), United Kingdom.

The visiting program was part of the activity schedule for one of the authors' post-doctoral fellowship at the University of Applied Sciences in Osnabrück, between November 2013 and October 2014, which received funding from the Coordination for the Improvement of Higher Education Personnel (CAPES), process number: 3235-13-0. The post-doctoral project was entitled: Palliative cancer care according to health professionals: a comparative study Brazil/Germany.

The visit to the hospice in Osnabrück was requested and previously scheduled with the head nurse, who served as a guide during the visit and granted an interview that took one hour and a half. The information collected was based on an interview script, as follows: what is the history of the hospice? How do people get access and what is their main clinical profile? How do relatives and volunteers participate? What is the main workforce and how is team care organized? How is the hospice funded? What are the main care activities? What are the main institutional challenges? In addition, structural aspects and the physical organization of the scenario were observed.

The visit to the Saint Christopher's Hospice was scheduled through the internet, as this activity is part of the institution's education and training program. It took four hours, including a visit to the facilities and explanations from different professionals about the history and general aspects of the service, when all questions selected in the interview script were addressed.

To describe the experience, the following aspects were considered: ambience of physical area; functioning of the institution; workforce; approach of main care activities; and main institutional challenges. This description was aimed at contributing to the dissemination of the hospice movement, which is under development in many countries, like in Brazil, underlining its importance and need in modern times.

What the ethical aspects of research involving human beings is concerned, ethical clearance was not required in Germany, waiving the use of the Consent Term to hold the interviews mentioned. Nevertheless, the post-doctoral project received approval from the Institutional Review Board at Anna Nery School of Nursing, *Universidade Federal do Rio de Janeiro* (Protocol number 439.069), as the proposing institution, as well as from the RIB at the INCA (Protocol number 460.522), as the co-participating institution in Brazil, in compliance with National Health Council Resolution Number 466/2012.

## RESULTS

### General characteristics of the hospices

The hospices visited are charitable institutions that are open to the entire population in need living near the cities where they are located. Saint Christopher's Hospice was the first to be created around the world along the modern model in London on July 24<sup>th</sup> 1967. Nowadays, it attends to approximately 2000 people per year. The institution is vital in the global dissemination of the hospice movement. The first palliative care team for home care purposes originated in this hospice in 1969.

The hospice in Osnabrück is 15 years old and has also gained publicity through information dissemination among the population. The hospice model is presented through different media, including lectures in schools; media channels; dissemination among people, including fundamental participation from volunteers; and by being open to visits from associations or groups, including people and representatives from other countries. Thus, its existence is increasingly disseminated.

In that sense, it is highlighted that Saint Christopher's Hospice possesses an important education and training center, inaugurated in 1973, with a defined agenda for each year, offering activities that are open to the general public and to volunteers, as well as other specific activities for health professionals. Each year, about 3,000 professionals visit and get trained, approximately 13% of whom come from other countries. The main course is multiprofessional and takes one week. Different other shorter courses exist though, linked to college programs, with a library and bookshop. The Osnabrück Hospice also has a small library.

Enrollments for the courses in general are done through the website, with costs proportional to the nature of the activity. In addition, several other leisure and play activities are offered, such as charitable luncheons, ecological walks, marathons and other festivals, also linked to special religious celebration dates, which not only disseminate the service and unite people, but also strengthen the link between the church and this movement and get funding.

The Saint Christopher's Hospice offers 48 beds, mostly in individual rooms, as there are only four nursing wards with four beds each. The architecture of the nursing wards allows them to receive ample daylight, with large glass windows. This concept is very common, besides the contact with nature, including the presence of gardens and open-air circulation areas. Each year, about 830 people pass through the wards, approximately 25% of whom are able to get back home with their pain or other symptoms under control. The mean length of stay at the nursing wards is between 14 and 16 days. The patients are free to choose how long they want to stay though. And, during their stay, they can choose to go home, whether to spend the night or at weekends, or even to go for a walk if their physical conditions permits this. It is highlighted that, in the home care modality, the patients remain about 19 weeks under the health team's monitoring and 50% die at home.

At the Osnabrück Hospice, the wards are located on the ground floor of a building, with a linear structure and 11 beds. The rooms are individual and reserved, with terraces that overlook the external area of the garden and with large doors to permit the passage of hospital beds. The patient's mean length of stay is about three weeks, slightly longer when compared to the mean length at the Saint Christopher's Hospice. And the area is open and structured to receive relatives, who stay as companions. The relatives are considered a care unit, whose needs are acknowledged, valued and attended to.

Regarding the epidemiological profile, most of the cases managed, whether at the nursing wards or in home cancer, are cancer patients (80%), like in the case of Saint Christopher's Hospice. The other conditions include: chronic obstructive pulmonary disease, dementia, Parkinson's disease, heart failure and neurological diseases.

Among the reasons to demand hospice care, difficulties to control symptoms at home are highlighted, like in the case of pain, dyspnea or the presence of a tumor wound. In addition, one of the main reasons is the difficulty to organize the family for care, mainly when its members work. Nevertheless, social problems involving abandonment are not common. In general, the families are always highly present.

After the demand to stay at the hospice is presented, a preliminary visit to the patient and his/her family takes place, whether at the hospital or at home, to permit clarifications about the premises and services available.

Most patients die at the hospice. In some cases, however, after the clinical condition that required their stay at the institution improves, the patients can return home and be reintegrated in the home care service or in the outpatient care available. In many European countries, however, home care is the main care modality in palliative care, which increases the statistics of the place of death being the home. The prerequisite for this result derives from the expansion of the outpatient network, besides the close cooperation among several professionals and volunteers.

When the patient dies, the physician is telephoned and, within two to three hours, he is present to certify and sign the death certificate. After the death, the family can say goodbye and the body can stay at the hospice for up to 24 hours to solve bureaucratic aspects involving the funeral service for example. The family is solely responsible for all of these services after the death.

### Main staff

About 300 people work at Saint Christopher's Hospice. The clinical staff consists of 222 people, who receive support from about 1,000 volunteers in all areas of the hospice. All volunteers receive training to be with the patients and their relatives, also to accompany the mourning phase, which can take up to 12 months. At the time of the visit, this training was offered once per week and took eight weeks.

Nurses are the main staff. At the hospitalization service of Saint Christopher's Hospice, the nursing human resources, which include baccalaureate nurses (60%) and healthcare assistants (40%), vary with the shift, that is: in the morning, one professional is present for every two patients; in the afternoon, one professional for every three or four patients; and at night, one professional for every five or six patients. All baccalaureate nurses should take the palliative care module as part of their undergraduate program, while the assistants should take credits on the theme for qualification purposes.

A physician is not present full-time. Instead, (s)he visits upon the patient's demand. At the Osnabrück Hospice, there is no specific physician, but mostly the professional who was already monitoring the patient's clinical evolution since the diagnosis of the disease. Hence, the physician visits every one or two weeks and, as (s)he is already familiar with the case, this makes the assessment easier.

In Germany, the nurses' three-year training takes place in nursing schools, followed by palliative-care training during a 120-hour program. The hospice also receives nursing students from these schools during their training for the sake of a practicum, which takes six weeks for each class. In total, 25 nurses work shifts, totaling 30 hours per week, shorter than the 40 hours per week established in the country. The institution has two head nurses who alternate their shifts to be present each day during the day shift.

The nurses are carefully selected and trained in compliance with relevant standards and qualifications, in line with the premises of palliative care. In addition, they receive support to cope with the reality of death and suffering.

Among the support staff, the cleaning and catering professionals are highlighted. The volunteers are responsible for simple tasks, which represent social activities, and do not engage in the specific care, which is the nurses' responsibility. At the time of the visit, 20 volunteers worked at the Osnabrück Hospice. Anyone can serve as a volunteer and receives preparation, qualification and support through regular meetings.

In Osnabrück, the catering attends to each patient's specific preferences. The main meals come from the hospital though, which is located in front of the hospice, and also offers other support and specialized services. The hospice kitchen is used to prepare small meals. If the families want to, they can bring food. When eating is impossible for reasons related to the evolution of the disease, mainly in case of the anorexia-cachexia syndrome cancer causes, the patients can be encouraged to simply smell the food if they want to.

At Saint Christopher's Hospice, the home care program includes six specialized nursing teams, who cooperate with the general practitioner who monitors the patients, as well as with other community services. The service is offered 24 hours per day, seven days per week. About 750 people are monitored at home. The nurse can attend to people in better clinical conditions at outpatient clinics for example.

The family itself can take the initiative to request a stay at the hospice, when they find out about the services the institution offers; or the clinics of origin can forward the patients, as well as other care modalities in the palliative care network. The patients' autonomy is preserved, as they can choose between palliative care or not and between going to the hospice or not.

When the patient is received at the hospice, the nurse takes an initial, complete interview to collect information on the disease but, above all, to get to know the patient's personality, desires and preferences. Patients can decorate the room as they want, including pictures and other personal objects, and most are allowed to bring their pet.

### **Other care activities**

Both hospices offer a social area that is very comfortable, similar to a house, a home, instead of a hospital. In this social area, several activities are offered, such as afternoon teas, when relatives of people who have passed away can be invited. In addition, there is a large room for the family to stay when their loved one dies. The patients and relatives have a book at their disposal to register their experience, which is open to the staff but not to visitors.

At the Osnabrück Hospice, when a person dies, everyone knows as a candle is ritually lit in the main corridor. In addition, there is a large veranda with a very pleasant social area that overlooks the garden. Sometimes, background music is heard in the social areas, or one of the volunteers playing the piano. There are pictures, mandalas that symbolically represent this phase of life and the symbol of the institution, which is a globe involved by a pair of hands.

To offer relaxation and comfort, a room is available with a hydromassage tub, where the patients can stay as long as they want and have teas or other drinks, including liquor. To get into the tub, a bed elevator system is available for patients who are bedridden or have locomotion difficulties.

At Saint Christopher's Hospice, a leisure center called the "Anniversary Centre" is available, which was created in 2009 after collecting funds to reform the ground floor. The center is open each day of the week, between 08:00 and 21:00 hours. The following is offered: social area for family members, caregivers and visitors in general with Internet access; a café and room to relax; a gym for rehabilitation; daily activity programs for patients and relatives who attend the outpatient clinic; the clinics, with appointments for medical, nursing, physiotherapy, psychiatry, social service, occupational therapy and complementary care, a chaplain, music or art or other creative activities; and a hairdresser. The nursing team receives and guides the people at this center with a view to the daily schedule, together with the multiprofessional team, besides directing people in home care but who can visit this center. Activities can be done individually or in group and also involve volunteers.

Besides the spontaneous demand to attend to this center's facilities, dynamic social activities take place to encourage

people to participate, such as: professional concerts, the community choir, Sunday lunch with live music and all-you-can-eat pizza or curry at night. In the fall of 2013, the chat activity called "Death chat at St Christopher's" was started, as a space to discuss death and dying, including orientations for care and for the funeral.

### Main institutional challenges

Among the current challenges the service is confronted with, the following stand out: attending to people with different diseases, the expansion needed beyond cancer; working directly with the family's presence; managing the service; and having sufficient funding. In Germany, the bureaucratic aspects are considered as challenges, including the need to fill out paperwork when the patient is received at the hospice, besides the specialized human resources. Although medical training includes a theoretical unit on palliative care, specialized education is still lacking in the country, which demands investments.

The care offered at the hospices does not come with any charges. Families are free to donate if they find that necessary.

At the Osnabrück Hospice, the institution's activities receive public funding, responsible for approximately 90%. The remaining 10% come from foundations and donations. In general, this amount does not vary, except in catastrophic situations that can overturn the donations to respond to other needs, which is not very common.

At Saint Christopher's Hospice, getting funding to offer the services is considered a challenge, demanding all members' commitment throughout the year, also aiming to better disseminate the services. Each year, 17 million British pounds are needed, obtained as follows: about 1/3 from public funds, 1/3 from legacies and the remainder from donations and funding activities, including charity shops and other resources.

## DISCUSSION

The World Health Organization (WHO) defines palliative care as an approach aimed at promoting the quality of life of patients and their families who face life-threatening disease-related problems together, through prevention and the relief of suffering, by means of the early identification, correct assessment and treatment of pain and other physical, psychosocial, emotional and spiritual problems. Concerning cancer, according to WHO, the tactics include prevention, early diagnosis, treatment and cure of the disease. In view of the current situation of this global epidemic and the need for a life-regulation policy, however, palliative care is presented, together with an orientation guide to create effective programs<sup>8</sup>.

Besides the deficit in terms of professional education in palliative care and other factors, however, the current challenges to disseminate this new care mode are confronted with a paradigmatic issue, when death is considered a failure, in view of the investments in cure and/or the maintenance of life at any

cost. Hence, one of the main difficulties medical professionals face is to acknowledge "palliative care patients". And, often, the patients die without enjoying the benefits of comfort and quality at the end of their lives<sup>4</sup>.

Thus, in palliative care, by acknowledging the dying process, the professionals can implement actions to achieve quality of life at the time of death. This demands resources and structure, considering the place where the care will be offered. The hospice is an option for palliative care, despite the greater trend towards home care. The countries/programs that offer this kind of service in the care network can offer this option to patients suffering from an incurable, progressing and symptomatic disease. Through communication, resulting from the entire team's efforts, the discussion of the preferred place to die can be included in the care planning; although challenging, this can be rewarding<sup>9</sup>.

In terms of service costs, the current picture shows a lack of good data to permit comparisons. It is highlighted, however, that such cost-effectiveness studies, undertaken in the United States about 30 years ago, lead to the increase in palliative care, and that more than 41% of people die at hospices today. In general, this type of investment demands different inputs and the availability of specialized staff. Beyond the economic cost for the institutions and systems, the outcomes can positively influence the patients who experience the dying process and the people around them, including family members and professionals. Thus, the following elements are highlighted: people-centered care; advised family members; appropriate symptom control and excellence in communication and care planning<sup>10</sup>.

In terms of human resources, the experiences mentioned strengthen the importance of the palliative care nurses' activities, being the main staff at the hospices. The nursing team in general has contact with patients and relatives more frequently, delivering fundamental professional care so as to reduce the human suffering in the phase of life that can be strongly marked by total pain, that is, which affects all dimensions of human beings. These professionals, like other professionals in the health team, need to receive advanced education on the theme, based on end-of-life care models and theories to guide daily practice<sup>11,12</sup>.

It is highlighted that specialized education is a prerequisite to hire staff at the hospices visited, besides the responsibility of both institutions to qualify new professionals, disseminating and strengthening the knowledge area.

Hence, the dissemination of models and successful experiences in countries that are developing palliative care is an important strategy, like in the case of Brazil.

About the palliative care situation in Brazil, in terms of the number of services, including all care modalities, the National Palliative Care Academy has been working towards this register, which includes approximately 93 services today, mostly in the form of specialized palliative care beds in hospitals, outpatient care linked to the pain clinic and home care. The availability of specialized beds is minimal though and restricted to large urban centers. In the specific case of hospices, despite the lack of

reliable quantitative records, the movement is recent and shows some initiatives, mostly concentrated in the state of São Paulo<sup>7</sup>. In general, in quantitative and qualitative terms, it is affirmed that this service availability is inferior to the population's needs.

This lack of palliative care services in Brazil results in a bad quality of death, a phase marked by extended or recurring hospitalizations at non-specialized institutions. To strengthen this information, data from 2010 are presented, disseminated by the Informatics Department of the Unified Health System (DataSUS), which confirm that the hospital is the main place of death, corresponding to 80% of cancer-related cases of death<sup>13</sup>. Although this information is incomplete, in that it does not distinguish palliative care-related cases, it does picture the reality.

Various aspects can be referred to in the dissemination of palliative care and the hospice movement. The encouragement of volunteer participation can be highlighted, for example, in view of the importance of this category to enhance the quality and range of palliative care. Appropriate training and advice for these people should be focused on, as the cultural complexity and participation in practical actions are important challenges.

Besides attention to the volunteers, care for family members is emphasized, who also need to be valued and attended to, besides the appropriate structure to receive them comfortably. It was evidenced that the hospice care modality can be an option when the family has no logistic, emotional or social conditions to take care of the patient at home. Hence, this alternative gains strength in view of the contemporary concept of family and family relations, evolving with fewer members. Nevertheless, it is highlighted that the decision to go to the hospice should be based on the patient's desire<sup>14</sup>.

As a result of the aspects observed during the visits, this initiative is valued in the palliative care context. In the current Brazilian public health system - the Unified Health System (SUS) - it is highlighted that this type of initiative can be private or public, and also involve social agents like non-for-profit/philanthropic institutions, which go beyond the logic of charity. The state of São Paulo has most accumulated experience in the articulation between the public and the private in health, through social organizations, particularly in primary care<sup>15</sup>.

Considering the obscure questions that remain with regard to the cost of this kind of care to people who are dying, as well as the taboos involved in death, the experiences described evidence the importance of dissemination means and means to integrate people, besides the encouragement of volunteer participation and the commitment to professional training. Different measures can be adopted to better disseminate palliative care in general, which should be encouraged in Brazil, mainly among health students and professionals, who need to know the ways to promote comfort and quality of life in this phase of the disease, in view of the multiple dimensions of human beings. The strong influence of feelings of love and solidarity is also evidenced, which are extremely necessary to drive this movement.

## CONCLUSION

The visits to the hospices enhanced ideas and knowledge exchange with international peers on this palliative care modality. Strategic issues could be observed and analyzed based on the precepts of this care mode, including: the physical structure needed; the institutions' way of functioning; the main staff, highlighting the nursing team, as well as the participation of volunteers; the main care activities and challenges. These issues were very similar at the hospices visited, although Saint Christopher's Hospice should be highlighted as a model, being the first hospice and responsible for the global dissemination of this movement.

Strategies to encourage visits to referral centers should be stimulated, whether in Brazil or internationally, so as to contribute to the increased dissemination of knowledge and successful practices, with a view to the personal and professional growth of people dedicated to palliative care practice and to cooperation between researchers and institutions, which is possible through technical visits for example. These strategies can be combined with professional training activities, so as to enhance the professionals, especially the physicians' awareness of the importance of palliative care, an activity as relevant as diagnosis and treatment. Therefore, this activity area demands plenty of dissemination. People need to be sensitized, a process that can take time but will offer good results for the health system and to live in a society based on love and solidarity.

For the advancement of palliative care and the hospice movement in Brazil, this experience report evidences a series of current needs, as well as the need for a national policy, education and the availability of medication; investments in research using methods that permit diagnosing, assessing and planning actions, as well as exploring the few Brazilian experiences, considering the administration mode and the possibility to explore partnerships, in view of the new social reality of service organization and public policies.

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