

DEINSTITUTIONALIZATION IN PALLIATIVE CARE: PROFILE OF USERS OF A UNIT IN RIO DE JANEIRO/BRAZIL*

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ABSTRACT: Objective: Gain knowledge on the profile of users of a residential care service provided by a hospital in Rio de Janeiro as part of a deinstitutionalization strategy for individuals in palliative care. **Method:** descriptive and retrospective study based on quantitative investigation. The medical records of patients who received care at a home care service from January 2012 to December 2016 (n = 655) were analyzed. Of these, 330 (50.4%) were women and 493 (75.3%) were older than 60 years. Most of them, 598 (91.3%) lived in the Metropolitan region of Rio de Janeiro and 406 (61.9%) have cancer. Regarding the demand for technical care, there was a prevalence of care related to skin lesions, 150 (22.9%); followed by oral feeding, 528 (80.6%); and gastrostomy, 123 (18.7%); ostomies, 178 (27.1%) and bladder catheter or cystostomy, 106 (16.1%). In addition, 424 (64.7%) users were entirely dependent on care. **Conclusion:** Regarding the profile of the users, most of them were elderly individuals entirely dependent on care and diagnosed with cancer. Strategies should be implemented for the management of these individuals.

KEYWORDS: Home care; Oncological nursing; Nursing care; Palliative care; Health management.

DESOSPITALIZAÇÃO EM CUIDADO PALIATIVOS: PERFIL DOS USUÁRIOS DE UMA UNIDADE NO RIO DE JANEIRO/ BRASIL

RESUMO: Objetivo: conhecer o perfil dos usuários do serviço de desospitalização de uma unidade no Rio de Janeiro. **Método:** estudo descritivo e retrospectivo, com base no método de investigação quantitativa. Foram analisados prontuários de pessoas atendidas no período de janeiro de 2012 a dezembro de 2016 (n = 655). A amostra é constituída por 330 (50,4%) usuários do sexo feminino, com 493 (75,3%) acima de 60 anos. Maioritariamente 598 (91,3%) residem na região metropolitana do RJ, 406 (61,9%) têm câncer. Relativamente à demanda de cuidados técnicos prevalentes são as lesões de pele, 150 (22,9%); a alimentação por via oral, 528 (80,6%); e gástrica, 123 (18,7%); estomias, 178 (27,1%); e sonda vesical ou cistostomia 106 (16,1%). Apresentavam dependência total, 424 (64,7%). **Conclusão:** o perfil dos usuários é composto predominantemente por idosos, com dependência total e patologia oncológica requerendo implementação de estratégias que visem a condução destes casos.

DESCRIPTORES: Assistência domiciliar; Enfermagem oncológica; Cuidados de enfermagem; Cuidados Paliativos; Gestão em saúde.

DESHOSPITALIZACIÓN EN CUIDADOS PALIATIVOS: PERFIL DE LOS USUARIOS DE UNA UNIDAD EN RIO DE JANEIRO/BRASIL

RESUMEN: Objetivo: conocer el perfil de los usuarios del servicio de deshospitalización de una unidad en Rio de Janeiro. **Método:** estudio descriptivo y retrospectivo, con base en el método de investigación cuantitativa. Se analizaron prontuarios de personas atendidas en el período de enero de 2012 a diciembre de 2016 (n = 655). La muestra tiene 330 (50,4%) usuarios del sexo femenino, con 493 (75,3%) mayores de 60 años. La mayoría, 598 (91,3%) viven en la región metropolitana de RJ, 406 (61,9%) tienen cáncer. Acerca de la demanda de cuidados técnicos, son prevalentes las lesiones de piel, 150 (22,9%); la alimentación por vía oral, 528 (80,6%); y gástrica, 123 (18,7%); ostomías, 178 (27,1%); y sonda vesical o cistostomía 106 (16,1%). Presentaban dependencia total 424 (64,7%). **Conclusión:** el perfil de los usuarios fue predominantemente de ancianos, con dependencia total y patología oncológica, siendo necesaria implementación de estrategias para el acompañamiento de estos casos.

DESCRIPTORES: Asistencia domiciliar; Enfermería oncológica; Cuidados de enfermería; Cuidados paliativos; Gestión en salud.

*Article related to the doctoral thesis titled: Gestão do cuidado à pessoa com câncer: Estratégias de ação para atuação multiprofissional no processo de desospitalização. (Management of care to individuals with cancer: Strategies for multidisciplinary action in the process of deinstitutionalization)

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Received: 07/07/2017

Finalized: 12/03/2018

● INTRODUCTION

The timeliness of the topic is reflected in the growing demand of people in palliative care, especially cancer patients, drawing attention to the need for “new technological arrangements”⁽¹⁾ for the promotion of care, through the coordination of a network of care and the guarantee of continuous healthcare delivery.

According to data from the World Health Organization (WHO) on the current status of the delivery of palliative care worldwide, cancer appears as one of the main chronic diseases, with the estimate of 27 million new cases, 17 million deaths and 75 million people living with cancer, for 2030, which demonstrates the need for coordinated actions and investments in health to meet such demand⁽²⁻³⁾.

The health care model must contemplate the changes in the epidemiological profile of the population characterized by the high incidence of chronic-degenerative diseases, especially cancer, and the need of palliative care because of the population aging and the changing lifestyles⁽⁴⁾.

Thus, the Brazilian Ministry of Health has been investing in policies and strategies to minimize the social impacts resulting from the magnitude of chronic health situations, promoting the quality of life of people under these conditions, as well as the integration and participation of their families, by providing care in settings other than hospitals.

The word “de-hospitalization”⁽⁵⁾ refers to the deinstitutionalization of hospitalized patients, a process aimed to facilitate discharge from hospital to home and the reintegration of the individuals in a care network, according to the principles of humanization, continuous care and family involvement, and based on one of the “central axes of home care”.

Home care is one of the possible ways to care for people with cancer requiring palliative care and their relatives, with the optimization of the care transition process, foreseen in Brazilian and international relevant public policies. Home care enables coordination at the different levels of the healthcare network, seeking strategies to eliminate the gaps in the care provided to the patients and their families in an integrated and multidisciplinary way⁽⁶⁻¹⁰⁾.

Considering palliative care as a “biopolitical device created for the benefit of the society”, it is appropriate to encourage planned and possible models of care that are already implemented worldwide and which are still incipient in developing countries, regarding the coordination and development of integrated actions, such as home care, hospices and cancer care services⁽¹¹⁻¹²⁾.

The search for hospital care, to the detriment of any other types of care models, reflects an attempt to cure the disease. However, with the impossibility of such cure, the network coordination of the health care aimed to ensure continuous care for these individuals still has gaps, and it is necessary to rethink alternatives, such as measures of deinstitutionalization in an integrated way, focused on the needs of persons with cancer and their families considered in their multiple dimensions.

Thus, deinstitutionalizing is more than the mere removal of a patient from the hospital setting. It is rather a measure to ensure that the actions initiated in the hospital are not discontinued, as well as the maintenance of the network coordination of care, in an integrated and human-centered approach.

Thus, seeking the valuation of deinstitutionalization in the scope of palliative care in cancer in Brazil as a health care strategy, the present study aimed to gain knowledge on the profile of users of a home care service that is part of a deinstitutionalization strategy provided by Hospital Federal Cardoso Fontes (HFCF) from Rio de Janeiro/ Brazil.

● METHOD

This study is part of a research paper about the process of deinstitutionalization of cancer patients in palliative care, from the perspective of the team and the family. The methodological design of this research is based on a descriptive and retrospective study, according to the assumptions of the quantitative research method.

A documentary survey (medical records) was carried out at Hospital Federal Cardoso Fontes (HFCF) in the Jacarepaguá neighborhood, in the city of Rio de Janeiro/Brazil, in a home care service (SADES) that is part of a deinstitutionalization strategy for individuals in palliative care in the transition from hospital to home.

For data collection, conducted from January to March 2017, the medical records of users of the residential care service during the January 2012-December 2016 period (n = 655) were assessed. The inclusion criteria were the medical records of patients monitored from the hospital discharge process to home care, with a consent form signed by a family member, considered a formal caregiver of the patient, upon arrival to the health service. The exclusion criteria were requests for opinions submitted to the health service, without the implementation of the deinstitutionalization process.

The data obtained were coded and typed in a spreadsheet and later analyzed using SPSS software version 21.0® (SPSS for Windows, Chicago, USA), and treated with descriptive statistics and presented in frequency tables with absolute values (n) and percentages (%) for the categorical variables.

The study was approved by the Research Ethics Committee of Anna Nery School of Nursing/ UFRJ and authorized by the co-participating institution, under Protocol No. 1,548,669. Regarding ethical aspects, issues involving human beings were observed according to Resolution no 466/2012 of the National Health Council of the Ministry of Health⁽¹³⁾.

● RESULTS

The study sample consisted of 655 people in palliative care, registered at the service during the study period. Table 1 describes the sociodemographic distribution of the users observed in their medical records.

Regarding gender representation in the study sample, it was equal, as follows: 330 women (50.4%) and 325 men (49.6%), since the slight difference in the number of men and women is not statistically relevant. Regarding the age group, most users were aged over 60 years: 493 (75.3%), and the families of 292 (44.6%) users were composed of 4 to 5 members. Most of these individuals lived in the metropolitan area of Rio de Janeiro, with 598 (91.3%) of the users distributed in different neighborhoods, but 57 (8.7%) lived in other municipalities outside Rio de Janeiro.

Table 1 - Distribution of users of the SADES, according to sociodemographic aspects. Rio de Janeiro, RJ, Brazil, 2017

Variables	Categories	n	%
Gender	Female	330	50.4
	Male	325	49.6
Age Range	≤ 18 years	02	0.3
	19 – 29 years	07	1.1
	30 – 39 years	26	4
	40 – 49 years	50	7.6
	50 – 59 years	77	11.7
	≥ 60 years	493	75.3
Family Composition	2-3 members	198	30.2
	4-5 members	292	44.6
	6-7 members	137	20.9
	More than 7 members	28	4.3
User residence	Metropolitan region of Rio de Janeiro	598	
	Other municipalities	57	91.3 8.7

Table 2 shows the distribution of the diagnoses of users of the service from 2012 to 2016. Regarding the diagnoses, most users had cancer, 406 (61.9%), with predominance of prostate cancer, 117 (17.9%), followed by breast cancer present in 98 (15%) of the cases. The other non-oncological diagnoses corresponded to 249 (38.1%) of the cases, with most users diagnosed with Alzheimer's disease: 109 (16.6%).

Table 2 – Distribution of the diagnoses of users of SADES / HFCF, Rio de Janeiro, RJ, Brazil, 2017

Variables	Categories	n	%
Types of diagnoses	Cancer	406	61,9
	Other diagnoses	249	38,1
Main diagnosis	Prostate cancer	117	17,9
	Breast cancer	98	15
	Lung cancer	31	4,7
	Cervical cancer	25	3,8
	Vulvar cancer	10	1,5
	Stomach cancer	46	7
	Alzheimer's disease	109	16,6
	HIV	2	0,3
	Sequelae of CVA/EVA	99	15,1
	Kidney cancer	20	3,1
	Colorectal cancer	35	5,3
	Pancreatic cancer	1	0,2
	Laryngeal cancer	2	0,3
	Anal cancer	2	0,3
	Various neurological disorders	39	6
	Ovary cancer	4	0,6
	Hodking's lymphoma	7	1,1
	Non-Hodking's lymphoma	1	0,2
	Thyroid cancer	4	0,8
	Brain cancer	3	0,5

Table 3 shows the distribution of the flow of users after deinstitutionalization in the 2012- 2106 period. The process of referrals to primary care totaled 221 (33.8%) and there were 337 (51.4%) deaths. In the distribution of referrals/year, no referral was performed in 2012, and 12 (1.8%) were performed in 2013, 26 (4%) in 2014, 117 (17.9%) in 2015, and in 2016 there were 66 (10.1%) referrals.

Regarding the number of deaths/year, there were 66 (10.1%) deaths in 2012, 48 (7.3%) in 2013, and 32 (4.9%) in 2014, 35 (5.3%) in 2015 and 156 (23.8%) in 2016. Regarding hospital readmission, it occurred in 24 (3.7%) of the cases.

Table 3 – Distribution of the flow of users of the SADES/HFCF after deinstitutionalization. Rio de Janeiro, RJ, Brazil, 2017

Variables	Categorias	n	%
Total number of referrals to primary care		221	33.8
Referrals to primary care/year	2013	12	1.8
	2014	26	4
	2015	117	17.9
	2016	66	10.1
Total number of deaths		337	51.4
Deaths/year	2012	66	10.1
	2013	48	7.3
	2014	32	4.9
	2015	35	5.3
	2016	156	23.8
Hospital readmission	Yes	24	3.7
	No	631	96.3

Table 4 shows the distribution of demand for care, home-based therapy and the level of dependence of the users of the service. Skin lesions occurred in 150 (22.9%) of the cases. Regarding the type of food-related care demands, 528 users (80.6%) were orally fed, 123 (18.7%) were fed by gastrostomy and four (0.6%) through nasoenteral tube.

Regarding the use of ostomies, these were identified in 178 (27.1%) of the cases, as follows: 123 (18.7%) gastrostomies, 18 (2.7%) tracheostomies, and 37 (5.6%) other ostomies (ileostomy, jejunostomy, colostomy).

It was found that 28 (4.3%) users were given oxygen therapy in the study period, and 106 (16.1%) used catheter-delay bladder or cystostomy. Oral or gastrostomy routes were used in 630 (96.2%) users; injected drugs in 13 (2%), serum therapy in 3 (0.5%), hypodermal route in 8 (1.2%), and transdermal route in 1 (0.1%). Regarding the level of dependence of care, most patients, 424 (64.7%) were totally dependent on care, while 170 (26%) were partially dependent on care and only 61 (9.3%) were did not require any care during the process of deinstitutionalization.

Table 4 - Distribution of demand for technical care, level of dependence of care and treatments provided to users of SADES/HFCF and in home care. Rio de Janeiro, RJ, Brazil, 2017

Variables	Categorias	n	%
Demand for technical care	Skin lesions	150	22.9
	Oral feeding	528	80.6
	Use of Gastrostomy feeding tube	123	18.7
	Nasoenteral tube for feeding	4	0.6
	Ostomies	178	27.1
	Gastrostomy	123	18.7
	Tracheostomy	18	2.7
	Other ostomies (jejunostomy. ileostomy. cystostomy. colostomy)	37	5.6
	Oxygen therapy	28	4.3
	Catheter-delay bladder/ cystostomy	106	16.1
Therapeutics used at home	Oral route or gastrostomy	630	96.2
	Injections	13	2
	Serotherapy	3	0.5
	Hypodermic injection	8	1.2
	Transdermal injection	1	0.1
Level of dependence	Total	424	64.7
	Partial	170	26
	Independent	61	9.3

● DISCUSSION

Sociodemographic data indicate the profile of users of a home-based care service (SADES) of HCFC that is part of the process of deinstitutionalization of hospitalized patients. The gender composition of the sample is equal 50.4% of women and 49.6% of men, since the slight difference in the number of men and women is not statistically relevant. The non-predominance of one gender in the study can be explained by the presence of urology and gynecology services specialized in the treatment of oncological diseases, which are very relevant in the health care network.

Another aspect that deserves mention concerns the individuals who, although not resident in the municipalities of the Metropolitan Region of Rio de Janeiro (8.7%), are users of the services provided by the HCFC. This may characterize a therapeutic itinerary in the search for specialized care, especially in cancer care⁽¹⁴⁾.

It is believed that these travels to large urban centers to get medical care can be related to the difficulty of early diagnosis and treatment of cancer in smaller municipalities. This causes overload in the specialized hospitals of the big urban centers, and jeopardizes the delivery of continuous care and the coordination of the care network.

Thus, it is important to ensure the coordination of deinstitutionalization services with primary care, favoring reception and referrals (33.8%) of individuals, despite the high percentage of deaths (51.4%), which often characterizes a late diagnosis or the use of a therapeutic itinerary that does not ensure resolute care.

Another relevant point is the low rate of hospital readmission (3.7%), which may be associated to the number of deaths or to the implementation of integrated health actions, which can and should be used, among other aspects, as a management mechanism in the optimization of hospital beds.

Therefore, the coordination and integration of the different spheres of the healthcare system in Brazil are an alternative to the increasing demand of people in palliative care, especially cancer sufferers, as they make extra-hospital care possible, with the participation of all those involved in the management of care.

Another aspect identified is the predominance of a family composition between of 4-5 members, which facilitates the process of deinstitutionalization, since a larger number of family members can be trained in the care process, contributing to the construction of a structure of mutual assistance in the family unit.

As shown in a study on the building of the competencies needed by caregivers of cancer patients, one of the ways in which they deliver home care is the integration of the members of a family, nuclear and extended. Thus, a pattern of care in which the greater involvement of other family members depended on their availability of time and their personal resources, is created⁽¹⁵⁾.

The family is undoubtedly a valuable asset in the process of caring for individuals with cancer, not only because of the emotional value of caring for the sick person, but also because of the economic value of this work invisible to society⁽¹⁶⁾.

Currently, healthcare systems must develop tactics to make them more sustainable, and caregivers - provided they are properly supported - can be a valuable resource.

Thus, a care policy that promotes feedback between formal and informal care, ensuring caregiver support and greater interaction between different spheres, is necessary in the healthcare system.

Given the profile of users of a home care service aimed to the deinstitutionalization of patients from a hospital, which include a significant number of women affected by breast, cervical and vulvar cancer and other pathologies with a profile for palliative treatment, it is important to reflect on the role of these women as representatives of informal care, considering their important role in society. When they are debilitated by a serious illness, the family-based care structure can be weakened.

A recent phenomenological study,⁽¹⁷⁾ carried out in Portugal, showed similar results, with a predominance of female caregivers, older than 65 years, presenting several comorbidities and reporting difficulties and negative feelings associated with the informal care process.

Therefore, it is essential that the two care systems (formal and informal) work together to ensure the well-being of dependent persons and informal caregivers⁽¹⁵⁻¹⁶⁾.

The demands for technical care identified in this study do not prevent hospital discharge, since deinstitutionalization measures can be adopted for the implementation of care. Such measures involve the training and participation of the caregivers, to ensure the maintenance of proper health conditions at home and the prevention of hospitalization that uses unnecessary hard technologies.

Awareness of intra- and extra-hospital teams about the concepts that permeate palliative care and effective management of the care process at all levels are essential for the development of these deinstitutionalization strategies.

Therefore, the process of deinstitutionalization should be initiated before the hospital discharge period, through contacts between the health teams and the patients' families on training to caregivers, maintenance of care at home, proper infrastructure for the optimization of care, clarification of doubts, early detection of complications, etc⁽¹²⁾.

Regarding the percentage of individuals with cancer who used the service assessed in this study (61.9%), which is much higher than the percentage of individuals with other diagnoses (38.1%), it is consistent with estimates for people living with cancer and needing palliative care in the future, especially in Brazil, with estimates of 600 thousand new cases in 2016 and 2017⁽¹⁸⁾.

The prevalence of prostate (17.9%) and breast (15%) cancer cases in this study setting leads us to reflect on the construction of a network of care to cancer patients, considering the estimates of this pathology and the high rates of these types of cancers, especially in the elderly in Brazil and Rio de Janeiro⁽¹⁹⁾.

Moreover, the number of prostate cancer patients (17.9%) showed a direct correlation with the demand for care presented regarding the use of bladder catheter or cystostomy (16.1%), regarding periodic changes at home and specific guidelines, which makes deinstitutionalization indispensable in the management of these processes, prevention of complications and unnecessary hospitalizations.

Thus, the implementation of deinstitutionalization actions that allow family participation in care, user's independence, hospital bed turnover and shorter hospital stay are essential in the planning and execution of coordinated and integrated health activities, aiming to promote the improvement and humanization of care and the optimization of hospital beds.

Thus, it is believed that referrals to primary care services are indispensable, for guidance and routine care to address less complex cases with less demand for technical care, providing the basis for dealing with subjective issues arising from emotional relationships, serious illnesses, or proximity to death⁽⁵⁾.

Another relevant aspect mentioned by some authors is the aging of the population, which is considered one of the main causes of chronic degenerative diseases⁽¹⁹⁻²¹⁾. This finding corroborates the present study that demonstrated the predominance of the population over 60 years. Thus, it appears that changes in the management and implementation of care for this population are necessary, considering the growing increase in the demands of these individuals.

The several implications of the disease-health process, especially in palliative care, reflect the search for a care that covers more than the physiological aspects and that contemplate quality of life and the reduction of suffering, ensuring integral and humanized care to the patients.

Further improvements are needed in the delivery of home care, especially regarding pain control and the adoption of routes of administration of medications other than oral or gastric, especially in the case of analgesia for people with chronic pain. The use of the hypodermic or transdermal route, for example, can provide greater effectiveness and comfort⁽²²⁾.

Therefore, knowledge of the process of delivery of health based on deinstitutionalization of the individuals allows us to reflect on ways to provide care that do not involve hospitalization, and to recognize the need to exchange care-related knowledge in order to meet the growing demand of care to sufferers of chronic diseases, especially cancer, and regarding palliative care.

Moreover, this profile demonstrates the need to discuss care alternatives, such as deinstitutionalization, which requires the development of joint strategies, aimed to ensure that care is provided on a permanent basis at home.

Broader discussions on the scarce levels of care of the health care network are also necessary, and the elaboration of a joint planning, with the definition of goals, aimed to facilitate deinstitutionalization and demystifying the delivery of care to individuals with cancer outside the hospital setting.

Ensuring the maintenance of out of hospital care, with a low rate of readmission of cancer patients, reaffirms the right of the individuals, and their families and health care teams, to freely choose their preferred place of care and the best possible quality of end-of-life care, with assessment of risks and benefits, so that the participation of the involved actors becomes essential in the process of care management.

Discussing wishes, fears and uncertainties that pervade the entire universe of care for cancer patients in the deinstitutionalization process requires sensitivity to transmit confidence, assist in the construction of care in an environment other than the hospital and favor the adaptations necessary to maintain care delivery.

Knowing the profile of a health care service favors, among other aspects, the elaboration and management of care targeted to a specific population, with the mapping of the characteristics of this population, so that the needs of each person and family are met during the discussions that precede hospital discharge.

In-depth studies on topics related to care to individuals with cancer are needed, especially palliative care. In Portugal, there has been an increase in the number of studies on palliative care in master's and doctoral theses. However, the authors who developed the study that points these data ⁽²³⁾ reported that there are still several gaps to be filled, which is similar to what happens in Brazil.

● FINAL CONSIDERATIONS

The present study allows concluding that the profile of the users of this service demonstrates the need to search for strategies to improve palliative care in different scenarios, aiming to optimize integrated actions and care network.

Therefore, training in palliative care for all health care network teams is urgently needed due to the growing demands of the target population.

The process of transferring palliative care to the individuals' homes brings to light the wishes, uncertainties and fears that pervade care delivery. The proper management of this process can minimize such factors, by empowering the sick persons and their families to actively participate in care.

Therefore, it is essential that the health team reflect on the implementation and management of the assistance provided to individuals requiring palliative care in the deinstitutionalization process, given the growth of this demand and the emergence of policies targeted to this issue that are being discussed and implemented worldwide.

The present study may encourage the development of further studies on the aspects that pervade the process of deinstitutionalization of people with cancer in palliative care and the family unit, focusing on aspects such as religion, family income, education, among others, for the reorganization of care in the deinstitutionalization process, based on the specific profiles of users and their families.

ACKNOWLEDGMENTS: To Escola Superior de Enfermagem of Coimbra and Hospital Federal Cardoso Fontes and the Coordination for the Improvement of Higher Education Personnel – CAPES – PhD Sandwich Program Abroad, protocol no 88881.132710/2016-01 and the Ministry of Health.

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