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Hospital discharge of patients with disabling neurological injury: necessary referrals to rehabilitation

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Abstract *The present qualitative study was conducted in the second semester of 2014 via interviews with 12 doctors and 13 nurses working as managers at a large hospital that serves as a reference center for urgent and emergent care in the Zona da Mata region of Minas Gerais State, Brazil. The study sought to identify the criteria that doctors and nurses use to discharge individuals with disabling neurological injury with instructions related to accessing physical rehabilitation programs. Thematic content analysis was used to examine data. The results show that the participating hospital managers still have difficulties providing adequate referrals to specialized rehabilitation services and that their patients' autonomy and independence for self-care are impaired as a result. We concluded that in addition to involving relatives and other caregivers in the discharge of patients with a neurological injury that impairs their self-care abilities, managers should assess the accessibility of the patient's home and make adequate referrals to rehabilitation services in the community in light of the poor dispersal of information about what is available within the Care for People with Disability Network.*

Key words *Hospital management, Disability assessment, Discharge planning, Rehabilitation centers*

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Introduction

The establishment of the Care for People with Disability Network[1] has led to a need for changes in the links among services and care facilities within the health system to expedite referrals for potential users of community-based rehabilitation programs. Data from the 2010 demographic census[2] indicate that individuals with disabilities and impairments represented 14.5% of the Brazilian population; this percentage has increased to 23.9%, i.e., 45.5 million in a total population of 190.7 million.

According to the World Health Organization's (WHO's) World Report on Violence and Health[3], 10% of the population of any country in times of peace exhibits some degree of disability. Adequate recovery of these individuals' family and social roles requires appropriate and timely therapeutic interventions that properly prepare them and their relatives for their hospital discharge.

Patients and their relatives and caregivers very often complain about the procedures that doctors and nurses use to prepare individuals with disabling neurological injury for hospital discharge; in particular, they voice concerns about the lack of knowledge on the subject and the difficulties such professionals have with helping to orient them and/or refer them to accredited rehabilitation programs[4].

Upon investigating the association between the discharge orientations provided by nurses and their methods for implementing and managing care for inpatients with spinal cord injury, a study conducted in the United States[5] found that the more time nurses spend orienting patients and caregivers toat-home care, the better the outcomes in terms of the patient's functional autonomy for self-care and acceptance of his or her new life condition.

It is known that dual leadership in hospital management involves specialized doctors and nurses, who also make administrative decisions regarding the preparation of patients for hospital discharge. Leaders in these settings tend to follow the ethos of their professional trainingand to exert power based on their specific knowledge and the specific environment they command, which is characterized by emergency situations and high risk. However, these leaders are often unaware of supplementary health services available outside the hospital walls, and consequently, patients are discharged without appropriate orientationforthemselves and their relatives[6].

Because patients' preparation for hospital discharge also directly or indirectly involves other staff members, integrated care should be emphasized because it naturally encompasses the view that the integration of services via healthcare networks is crucial[7].

Among the interventions available to meet the aforementioned demand, rehabilitation, a field of knowledge and a practical approach thatenables people to learn new skills for coping with obstacles in daily life, must be considered[8,9].

As a service, rehabilitation comprises a set of healthcare actions and thus is an indispensable component of health promotion, disease prevention and helping patients, their family and community remain in good health and enjoy satisfactory levels of well-being[10,11].

Quality management at hospitals requires that the entire administrative structure commits to the changes required, as constant effortsare needed to ensure that the entire staff and the various hierarchical levels incorporate the actions and beliefs associated with the quest for continuous improvement[12].

Studies conducted in several countries (including a study of efforts to improve instruments to assess the length of stay in neurological rehabilitation at specialized hospitals in Germany[13] and a study that aimed to identify the best inter-professional practices of rehabilitation staff in Canada[14]) illustrate the urgent need to adopt new multi-professional behaviors that can reduce costs and increase the levels of satisfaction with care among patients, their relatives and the community.

From the primary care perspective, one study that sought to evaluate the quality of health and primary care services analyzed quality indicators in 44 hospital discharge reports from five different Italian regions[15]. The results showed little variation in the performance ranking of the services provided to populations in urban or rural areas and found that the use of quality indicators was efficient for evaluating costs, management and the satisfaction levels of service users.

Conceived as one of the basic principles underlying the Unified Health System (Sistema Único de Saúde - SUS), integrated care is the fruit of the efforts of professionals from multiple disciplines. It represents the convergence of the various types of knowledge exhibited by these professionals– in the case of the present study, the staff at anurgent care and emergency hospital – in the search for ways to ensure that the work flow is systematic and meets actual demands[16].

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Considering the changes introduced by Ordinance of the Ministry of Health no. 793/2012[1] and the demands of health service managers, the aim of the present study was to identify the criteria used by doctors and nurses to prepare patients with disabling neurological injury for hospital discharge and their instructions regarding physical rehabilitation programs.

Method

The present descriptive and qualitative study complied with the guidelines included in the National Health Policy for People with Disabilities and the Care for People with Disability Network[4]. The participants were nurses and doctors working as managers of inpatient wards at Holy House of Mercy of Juiz de for a (Santa Casa de Misericórdia de Juiz de Fora), Minas Gerais (MG), Brazil, a large reference hospital for the region known as Zona da Mata.

The sample included 13 nurses and 12 doctors with managerial positions at the hospital'surgent care and emergency departments, clinical and surgical wards, and intensive care units and whose job description includes preparing patients with disabling neurological injury for discharge and referral to specialized services in the community.

Managers from a variety of therapeutic settings were included on the basis of theirinvolvement in addressing the concerns of patients'relatives, as the patients in the present study required long-term at-home care.

Inclusion criteria

A managerial position at one of the Holy House of Mercy of Juiz de Fora's inpatient units; responsibility for preparing patients with a disabling neurological injury for discharge; age older than 20 years; agreement to participate; and the signing of an informed consent form.

The study complied with national and international ethical guidelines for human and animal research and was approved on July 21, 2014 by the UNIRIO research ethics committee, ruling no. 724,614.

Sample characterization

A total of 22 female (80%) and 3 male (12%) managers participated in the study. Their ages varied from 27 and 70 years old. The time since graduation varied from 2 to 45 years, as did the time spent working on the unit. The duration of work experience at the institution varied from 3 to 45 years.

Data production

Data production took place in November 2014 using individual interviews with a semi-structured script elaborated by the investigators. The interviews were scheduled in advance according to the participants' and the investigators' availability and were conducted in a secluded room at the hospital to avoid interruptions.

The interviews were audio taped and then transcribed using Word. The interview script comprised the following questions: What criteria do you apply to decide on the hospital discharge date for patients with neurological, post-traumatic or disabling sequelae? What do you do to prepare such patients for discharge?

Data analysis method

Content analysis – specifically, thematic analysis[17] – was performed in three steps: pre-analysis (unfocused reading and hypothesis formulation), explication of the material (coding and classification into categories) and treatment and interpretation of results (reflection). The raw text was coded according to thematic categories related to the managers' knowledge and actionsregarding the referral of discharged patients to the healthcare network.

The categories were analyzed according to the following principles: equal opportunity, development of accessible environments and social inclusion; integrated health care with ensured access to primary and specialty care, rehabilitation and other necessary procedures, as recommended by the SUS National Health Policy for People with Disabilities.

To protect the participants' anonymity in the transcripts, the following code was used: [Profession and interview order number], using the abbreviations NUR (nurse) and DOC (doctor).

Results

The raw data were organized as recording units according to the themes described in the Charts 1 to 4.

The organization of the themes included in the four charts above through content analysis

resulted in two theme categories: 1) Exclusively medical and staff-shared criteria; 2) Preparation for discharge and related issues.

Discussion of categories

Category 1: Exclusively Medical and Staff-Shared Criteria

The data corresponding to this category show that some of the doctors and nurses with

Chart 1. Exclusively medical criteria.

Order	Recording units
1	*Here, the one who decides on discharge is the doctor […].Relative to hospital discharge, we also use Fugulin's scale to give the appropriate orientation* (NUR 2).
2	[...] *The doctors are the ones who decide on the patients' discharge* […]. *We use the Patient Classification System (PCS)* (NUR 3).
3	*Discharge is decided by the doctor. I record the patients' daily progression according to Fugulin* […]. *I also use the Patient Classification System* (NUR 12).
4	*Functional capacity is assessed from the neurological point of view using the Rankin scale, and for patients with spinal cord injury, it is assessed using the American Spinal Association scale, a scale established by the American Spinal Injury Association* (DOC 3).
5	*First, we use the Glasgow Coma Scale. If the score is below 8, the patient has practically no chance of being discharged* (DOC 8).
6	[...] *A patient is in the condition for hospital discharge when he no longer depends on intravenous drugs or antibiotics and can be treated at home* […], *is in the condition to be treated at home, he only needs palliative care or care and motor evaluation* (DOC 10).
7	*We use that questionnaire for instrumental activities of daily living. With it, we get a very good functional assessment of patients; in addition, the scales specific to neurology, motor, sensory deficits are specific to this specialty, to our work* (DOC 11).

Chart 2. Staff-shared criteria.

Order	Recording units
1	[...] *Our patients here are very dependent; many patients have sequelae of stroke* […]. *We've got a multi-professional discharge summary, with physical therapy, doctors, nutritionist and nurses* (NUR 7).
2	[...] *The criteria you use to decide on discharge should be followed up by social workers* (NUR 10).
3	*It's not only a medical decision regarding their clinical state, but also a multidisciplinary issue* (DOC 6).
4	[...] *We discuss with other specialists and prepare [them] for discharge* (DOC 7).
5	[...] *it involves the full care provider staff, doctors, nurses, physical therapists, all those who provide care. Social workers, too; they play an essential role in ensuring that the patient will receive continued care after discharge. We learn through the social workers about the difficulties of finding options for transfer and a place where the patient will receive adequate care* (DOC 12).

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Chart 3. Family participation and orientation to care.

Order	Recording units
1	*We communicate with the family, tell the family, explain everything that should be done, the patient's state, what he will need, his level of dependence* (NUR 3).
2	[...] *The family should be involved all throughout the patient'sstay at the hospital. It's not just at the time of discharge that they have to be there, but they have to be involved* (NUR 9).
3	*I call the family, discuss what can be done at home, if there are conditions for support at home* […]. *I send [them] home* (DOC 3).
4	[...] *When there aren't, I call the hospital social workers* (DOC 3).
5	*As a rule, we put multidisciplinary staff and relatives in contact* (DOC 8).
6	*The doctor himself and the nurses, all those provide orientation on the care to be delivered at home* (DOC 8).
7	*I try to orient the family regarding the patients' care, even the patient himself regarding his own care* (DOC 9).
8	[...] *Which I believe might limit or disable the patient* […] *attempts are made for the patient to assume his self-care* (DOC 9).

Chart 4. Referral to primary care services.

Order	Recording units
1	*We refer [them] even to reference Basic Health Units (UnidadesBásicas de Saúde- UBS)* (NUR 2).
2	[...] *Giving orientation to relatives and patients about their rights, about the medication the SUS network will provide them* (NUR 5).
3	*I orient the family to seek the family health program at the local UBS to get a care provider at home* (DOC 4).
4	[...] *I orient the relatives to also claim their own rights* (DOC 4).
5	[...] *If there's one in the area, UBSs are the place that provide care to patients* (DOC 4).
6	[...] *A structure should be created at home, and a multidisciplinary staff should provide care* (DOC 6).
7	[...] *The home conditions need to be adjusted* (DOC 6).
8	[...] *Remove steps, increase the size of doors, put in an anti-slip floor, place grab bars in bathrooms* (DOC 6).
9	[...] *The family's preparation for discharge means adjusting the environment to the needs of the people who'll need that environment* (DOC 6).

managerial positions believe that decision to discharge patients with disabling neurological injury should be made solelyby doctors. In addition, (NUR 2, NUR 3, NUR 12, DOC 3, DOC 8, DOC 10, DOC 11) further observed that as it hashistorically evolved, medical knowledge is absolute,

whichovertly contradicts the principles of integrated and intersectorial health care[7,18].

It is known that doctors at emergency departments in hospitals in the United States[19] *frequently have access to clinical criteria for patients'discharge, for shared decision-making with the staff, and for referring patients to services that are likely to continue the previously delivered care, exactly as the Brazilian SUS recommends. This is corroborated by a study performed in the United States, which presented evidence that the procedure for hospital discharge is more advanced there, as shown by reduction of the frequency of adverse events and greater patient satisfaction with their knowledge about their own condition*[20].

In this regard, Chart 2 shows that the participating managers were open to the use of staff-shared criteria, as the narratives by (NUR 7, NUR 10, DOC 6, DOC 7, DOC 12) indicate; i.e., they were willing to consult all other staff members for additional information that could contribute to the discharge process. These findings show a positive progression in the understanding that no single profession can claim to have full knowledge of all health-related matters. An approach that is more attuned to the principles of integrated care and an interdisciplinary approach might help patients and their relatives to better understand the orientations given by each staff member; however, the idea that hospital management should remain centered on the influence of doctors/nurses still predominates[6,7].

Regarding the assessment criteria use by the participating doctors, only one of them (DOC 8) reported using the Glasgow Coma Scale[21] to make discharge decisions, while another one (DOC 3) said he used the Rankin scale[22] by the *American Spinal Injury Association* to assess patients with neurological injury, specifically those with spinal cord injury.

According to the study results, two nurses (NUR 3 and NUR 12) used the Patient Classification System (PCS) as criterion for discharging inpatients with disabling neurological injury. The Federal Nursing Council Resolution no. 293/04[23] established the PCS as a tool for determinepatients' degree of dependence on the nursing staff; the PCS can be used to calculate the time nurses spend providing direct and indirect care and the qualifications needed to meet the biopsychosocial and spiritual needs of patients[24].

It should be noted that the PCS also provides information that can be useful for decisions regarding the allocation of human resources, productivity monitoring and the cost of nursing care and for organizing services and planning nursing care. These elements are highly relevant to the planning and delivery of care to dependent patients, such as those discussed in the present study.

It is worth observing that nurses provide care to patients undergoing rehabilitation both at the early post-injury stage and in the long term. The aim of nursing actions is to promote patients' recovery and their adjustment to the limitations imposed by their disabilities and to address the individual needs of each patient and his/her relatives, particularly their functional, motor, psychosocial and spiritual needs. At the same time, nurses seek to help patients become independent despite the physical, cognitive and behavioral limitations imposed by their disability[25].

This specialized type of care combines the knowledge and actions of professionals from several different fields. This type of care also requires efforts to ensure patients'inclusion in prosthesis-fitting programs, the identification of assistive technologies, functional assessments of activities of daily living and self-care and preparation for at-home care. In addition, early intervention is important for patients with disabling neurological injury, who should be referred to Care for People with Disability Network services to receive adequate care.

Category 2: Preparation for Discharge and Related Issues

The hospital staff should seek to involve relatives and/or home caregivers in discharge preparations for individuals facing probable or possible limitations to their basic care. The majority of the participants in the present study reported involving relatives and caregivers in the hospital discharge process (NUR 3, NUR 9, DOC 3,DOC 8, DOC 9). Some participants reported concerns with discharge-related matters, such as referral to SUS primary care services/sectors (NUR 2, NUR 5, DOC 4, DOC 6).

Hospital-based health managers do not have a broad perspective regarding the referral of patients with disabling neurological injury to primary care supplementary services; that is, they do not consider such referralessential to complying with the guidelines of the Care for People with Disability Network[1]. Members of the Regional Inter-Managerial Councils (Conselhos Intergestores Regionais - CIR) and other public managers from all three governmental spheres are charged with allocating financial resources to more widely disperse information about

this public policy through mass media andother means of disseminating information about the health programs within the SUS.

When performed adequately, the involvement of patientswith disabling neurological injury and their relatives and significant others in preparations for hospital discharge can facilitate access to physical rehabilitation programs and early intervention. Within the context of rehabilitation, decisionmaking involves several steps[8,10,11,26]: the collection of initial data, a definition of the nature and severity of problems, risk prediction, the definition of the aims of intervention, program development and the selection of specific actions on an individual basis. Therapeutic strategies for rehabilitation, even the most basic ones, should be implemented before patients with functional disabilities are discharged.

The participants in the present study reported that in addition to involving home caregivers and the patients themselves in the preparation for hospital discharge, they also seek help from the institution's social workers to provide orientation regarding the services available in the community (DOC 3). Similarly, some participants reported concerns with the orientations on at-home care (DOC 3) and with efforts to prepare patients for self-care (DOC 9).

Self-care is included in the series of orientations given by the staff, particularly the nurses. Rehabilitation is a part of nursing care,both as a specialty and as a healthcare model. Rehabilitation efforts must begin with the first contact with the patient. The principles of rehabilitation are a basic component of health care, even in the absence of physical disability and related impairments, when one considers the care model applied in rehabilitation, which is essentially preventive and educational and targets the patient/family caregiver pair[10,27].

Consistent with the results of the present study, one study performed at six rehabilitation centers in the United States[28] evaluated the outcomes of the multi-professional care provided to 1,376 individuals with spinal cord injury at the time of discharge and one year post-injury. The study found that greater functional gains were associated with more time in physical and occupational therapy, and greater gains insocial integration were associated with more time in therapeutic recreation. Additionally, pressure ulcers either did not occur or were adequately treated, especially by the nursing staff.

Regarding post-discharge referral to SUS primary care services, the participants in the present study reported choosing Basic Health Units (Unidades Básicas de Saúde - UBS) – (NUR 2), (NUR 5) or telling patients and relatives how to obtain information about their right to care delivery at home (DOC 4). Mentions of matters related to accessibility stand out, as they are crucial for the at-home care of individuals with functional dependence and reduced mobility. In this regard, the professionals are responsible for providing information about the width of doorways, the need for anti-slip flooring and the placement of grip bars in bathrooms (DOC 6).

Regarding the staff orientations aimed at promoting patients' quality of life (QoL) after discharge, when they have to deal with daily living, one study that assessed cross-cultural issues related to the QoL of individuals with spinal cord injury (SCI) compared data collected in two different countries (United States and Brazil) through the application of the International SCI QOL Basic Data Set. The conclusions point to the need to improve that instrument as a function of the diversity of sociocultural factors related to promoting QoL among individuals with spinal cord injury[29].

It is known that many factors can influence the QoL after trauma, such as the quality of the care provided by the health system, the type and severity of injury, the number of surgical interventions, the degree of sequelae, pain, access to rehabilitation and socioeconomic status, among others. Consequently, the systematic assessment of patients throughout the post-trauma period could reflect the healthcare conditions in a given area and identify the equipment and institutional services needed for the psychosocial reintegration of patients after hospital discharge[30].

Many of the patients treated at the emergency and urgent care department of the hospital investigated in the present study exhibit a history of brain injury, which requires the staff to make decisionsabout their due referral to services affiliated with the Care for People with Disability Network. A practice-based evidence study conducted with 2,130 patients with traumatic brain injury at discharge after a nine-month stay at ten rehabilitation centers in the United States[31] captured variations in cognitive and functional gains that allowed the corresponding staff members improve the quality of rehabilitation practices to benefit all patients according to their individual needs.

As the present study emphasizes, records that include information on the progression of each patient contribute to the implementation of

therapeutic strategies adequate for the rehabilitation process. In this regard, a prospective study conducted in the United States with 450 adults after hospital discharge[32] sought to establish the prevalence of risk factors through a review of care providers' orientations, as registered in the medical records. The results showed that social isolation and treatment discontinuation were the result of patients' non-comprehension of the instructions given by the staff.

Upon assessing the effect of socioeconomic stratification on the well-being of patients with spinal cord injury at two rehabilitation centers in the states of Alabama and New Jersey, United States[33], one study found that the odds of depression, dissatisfaction with life and loss of self-esteem were higher among the participants who resided in areas were community-based specialized services were scarcer. This might also be the case for patients with disabling neurological injury after discharge from Holy House of Mercy of Juiz de Fora, as they reside in urban or rural areas in which community-based health and rehabilitation services might or not be available when they are most needed.

Conclusion

One may conclude that although the participating health managers were unaware of the processes/principles established by SUS to orient neurological patients at discharge and ensure that they receive information regarding the Care for People with Disability Networks units in an objective and systematic manner, the managers indicated joint efforts to change the understanding of interdisciplinary work, as characterized in the four charts presented above:1) the use of exclusively medical criteria; 2) the shift to staff-shared criteria; 3) the involvement of relatives; and d) articulation with other health care services.

The results of the present study also to point to changes in professionals' views and their understanding of integrated care, which might contribute to a coherent decisionmakingand wider sharing of competencies related to the expectations, risks, health, recovery and rehabilitation of their patients.

Finally, we do not pretend to have exhausted this topic; rather, we have merely highlighted some issues for the professional leadership in hospital management to consider regarding the importance of involving patients' relatives in meeting long-term care needs and of orienting patients with disabling neurological injury for discharge to ensure their access to rehabilitation programs, as recommended in the Care for People with DisabilityNetwork guidelines.

Collaborations

WCA Machado participated in the conception and design of the study, the analysis and interpretation of the data, the writing and critical revision of the manuscript, and the revision and approval of the version for publication. VM Silva participated in data collection, analysis and interpretation; writing and critical revision of the manuscript, and revision and approval of the version for publication. NMA Figueiredo participated in data interpretation, writing and critical revision of the manuscript, and revision and approval of the version for publication. RA Silva, EMC Branco, MA Carreiro, LK Rezende and RL Ramos participated in the critical revision of the manuscript.

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