

# Therapeutic itinerary of post-stroke patients: the state of the art of Brazilian scientific production

*Itinerário terapêutico de pacientes pós-acidente vascular cerebral: o estado da arte da produção científica brasileira*

*Itinerario terapéutico de pacientes postaccidente cerebrovascular: el estado del arte de la producción científica brasileña*

Andreza Maria Luzia Baldo de Souza<sup>1</sup>, Marcelo de Castro Meneghin<sup>2</sup>, Pedro Augusto Thiene Leme<sup>3</sup>

**ABSTRACT** | The study analyzed the qualitative research conducted in Brazil on the rehabilitation itinerary of patients who have suffered a stroke and synthesized its main contributions in search of the underlying senses and meanings. The integrative literature review was based on the question: how are the rehabilitation itineraries of stroke patients described in qualitative studies? BIREME, MEDLINE, LILACS, and SciELO databases were consulted, using the DeCS/MeSH descriptors: “acidente vascular cerebral AND qualitativa”; “reabilitação AND acidente vascular cerebral”; “acidente vascular cerebral”; “pesquisa qualitativa”; “acidente vascular encefálico AND qualitativa”; “reabilitação AND acidente vascular encefálico.” A total of six articles were included, which highlighted the importance of integrality of care, the role of the family in the recovery process, the centralization of services, the difficulty with transportation, and the unavailability of family members and caregivers as obstacles in the rehabilitation itinerary. Such results reinforce the need to improve the pathway of care of the patient who suffered a stroke and the demand for integrality of management.

**Keywords** | Stroke; Rehabilitation; Qualitative Research.

**RESUMO** | O estudo analisou as pesquisas qualitativas realizadas, no Brasil, sobre o itinerário da reabilitação de pacientes que sofreram acidente vascular cerebral (AVC), e sintetizou suas principais contribuições em busca dos sentidos e significados subjacentes. A revisão integrativa da literatura partiu da seguinte pergunta: como são descritos os itinerários da reabilitação de pacientes que sofreram um AVC nos estudos qualitativos? As bases consultadas foram BIREME, MEDLINE, LILACS, SciELO, utilizando os descritores DeCS/MeSH: “acidente vascular cerebral AND qualitativa”; “reabilitação AND acidente vascular cerebral”; “acidente vascular cerebral”; “pesquisa qualitativa”; “acidente vascular encefálico AND qualitativa”; “reabilitação AND acidente vascular encefálico”. Foram incluídos seis artigos, que destacaram a importância da integralidade do cuidado, o papel da família no processo de recuperação, a centralização dos serviços, a dificuldade com transporte e a indisponibilidade dos familiares e cuidadores como obstáculos no itinerário da reabilitação. Os resultados reforçam a necessidade de implementar melhorias no percurso de cuidado do paciente que sofreu AVC e a demanda pela integralidade do manejo.

Study conducted for the achievement of the Professional Master's degree in Management and Collective Health at the Piracicaba Dental School, University of Campinas (FOP/Unicamp) – Piracicaba (SP), Brazil. Paper presented at the 23rd National Meeting of Administrators and Technicians of the Public Dental Service (ENATESPO) and at the 14th Brazilian Congress of Collective Oral Health, held from November 4 to 6, 2020, online.

<sup>1</sup>Universidade Estadual de Campinas (Unicamp) – Campinas (SP), Brazil. E-mail: andrezamlb@gmail.com. ORCID-0000-0002-6575-2209

<sup>2</sup>Universidade Estadual de Campinas (Unicamp) – Campinas (SP), Brazil. E-mail: meneghim@unicamp.br. ORCID-0000-0003-2673-3627

<sup>3</sup>Universidade Estadual de Campinas (Unicamp) – Campinas (SP), Brazil. E-mail: pedroleme3@gmail.com. ORCID-0000-0003-3894-3189

**Descritores** | Acidente Vascular Cerebral; Reabilitação; Pesquisa Qualitativa.

**RESUMEN** | Este estudio analizó la investigación cualitativa realizada en Brasil sobre el itinerario de rehabilitación de pacientes que habían sufrido accidente cerebrovascular (ACV), y sintetizó sus principales contribuciones en busca de los sentidos y significados subyacentes. La revisión integradora de la literatura partió de la siguiente pregunta: ¿Cómo se describen los itinerarios de rehabilitación de los pacientes post-ACV en los estudios cualitativos? Las bases de datos consultadas fueron BIREME, MEDLINE, LILACS, SciELO, utilizando los descriptores DeCS/MeSH: “accidente vascular cerebral

AND qualitativa”; “reabilitação AND acidente vascular cerebral”; “acidente vascular cerebral”; “pesquisa qualitativa”; “acidente vascular encefálico AND qualitativa”; “reabilitação AND acidente vascular encefálico”. Se incluyeron seis artículos que destacaron la importancia de la atención integral, el papel de la familia en el proceso de recuperación, la centralización de los servicios, la dificultad de transporte y la indisponibilidad de familiares y cuidadores como obstáculos en el itinerario de rehabilitación. Los resultados refuerzan la necesidad de implementar mejoras en el curso de la atención a los pacientes post-ACV y la demanda de un manejo integral.

**Palabras clave** | Acidente Cerebrovascular; Reabilitación; Investigación Cualitativa.

## INTRODUCTION

Stroke is the second greatest cause of death in the world, accounting for 5.7 million deaths in 2016<sup>1</sup>. According to the Ministry of Health, every five minutes a Brazilian dies because of stroke, resulting in more than 100,000 deaths per year<sup>2</sup>.

Besides deaths, stroke is responsible for producing sequels, as described by the National Survey of Health (PNS)—a household-based epidemiological survey conducted by the Brazilian Ministry of Health in partnership with the Brazilian Institute of Geography and Statistics (IBGE)—which estimates that, in 2013, 570,000 people live with severe disability in Brazil<sup>3</sup>.

Stroke can cause sequelae related to motor, sensory, cognitive, and emotional functions, requiring a multidisciplinary care approach. Late assistance is associated with more severe disability and a longer process of functional recovery<sup>4</sup>. The resulting physical and psychosocial consequences usually require prolonged care<sup>5</sup>.

Difficulties in accessing health services and lack of follow-up services limit the opportunities for patients to obtain support after stroke<sup>6</sup>. Because it is a time-dependent condition, the sooner the patient is cared for after a stroke, the better the prognosis.

The success or failure of this initial therapy influences future demands for follow-up in the individuals' rehabilitation process. Thus the importance of reviewing the available knowledge on the therapeutic itinerary (TI) to analyze its state of the art and inform the gaps and opportunities to explore in future studies. The TI is the construction of the

trajectory of events and decision-making of an individual or group, with the treatment of the disease as the main objective<sup>7</sup>.

The integrative review aims to gather and synthesize research results on a given theme or issue in a systematic and orderly manner<sup>8</sup>. The objective of this review is to analyze the qualitative studies conducted in Brazil on the rehabilitation itinerary of stroke patients and to synthesize their main contributions, in search of the underlying senses and meanings.

## METHODOLOGY

The following steps were followed, according to the referenced method about integrative literature review: selection of the research guiding question; definition of the specific objective; data collection within the previously established inclusion and exclusion criteria; categorization; evaluation of the included studies; analysis of results, and knowledge synthesis<sup>9,10</sup>.

The study started with the following question: how are the rehabilitation itineraries of stroke patients described in qualitative studies? To conduct the study, the following health sciences descriptor terms (DeCS/MeSH) were used: “acidente vascular cerebral AND qualitativa”; “reabilitação AND acidente vascular cerebral”; “acidente vascular cerebral”; “pesquisa qualitativa”; “acidente vascular encefálico AND qualitativa”; “reabilitação AND acidente vascular encefálico.” Data was collected from articles published in journals indexed in the Virtual Health Library, comprising BIREME, MEDLINE, LILACS, SciELO, and specific health journals.

The following inclusion criteria were considered: (1) scientific articles conducted in Brazil; (2) articles from qualitative studies; and (3) articles related to the rehabilitation process. Exclusion criteria were: (1) articles conducted outside Brazil; (2) not related to qualitative research; and (3) without reference to the rehabilitation process. No publication cut-offs date were established for the inclusion.

The search for the articles was conducted from February to March 2019. Based on the combination of these

descriptors, 729 articles were found; of these, 725 remained after removing duplicates. In the screening, 164 were selected and 561 were excluded, leaving 44 eligible articles; of these, 38 were excluded, and six articles describing qualitative studies conducted in Brazil were included, which provided the corpus of this integrative review (Figure 1).

For extracting the information from the articles, a registration was performed considering the following variables: subjects, methodology, sample size, analysis methods, and concepts employed.

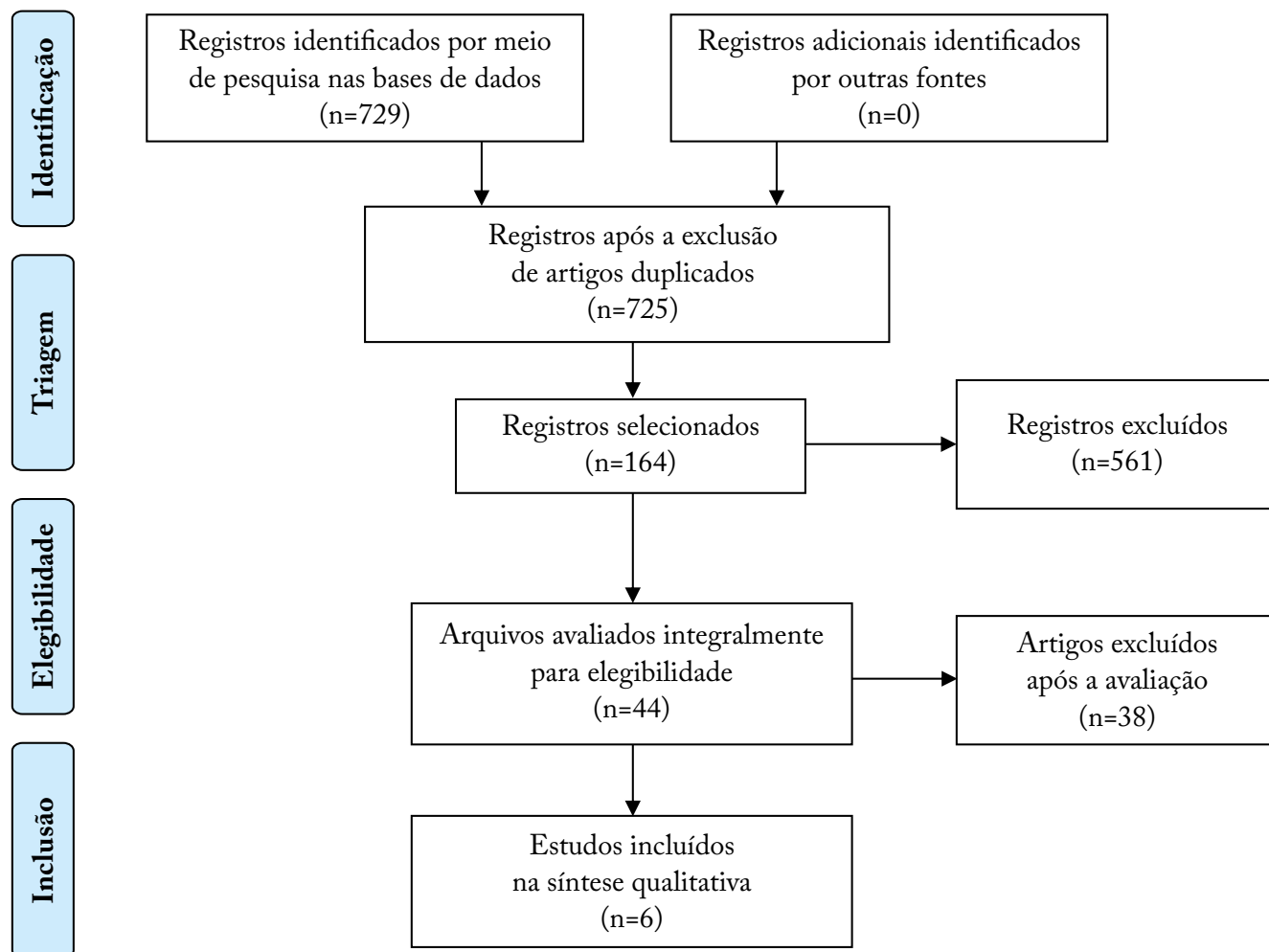


Figure 1. Flowchart of identification, filtering, and inclusion for the integrative review

## RESULTS

### Characterization of the studies

The articles differed regarding sample size, year of publication, and location in Brazil (Table 1). The samples

ranged from 6<sup>11</sup> to 16<sup>12</sup> subjects and were collected in the inland Northeast of Brazil (municipality not specified)<sup>13</sup>; Florianópolis (SC)<sup>14</sup>; Sobral (CE)<sup>10</sup>; Ijuí (RS)<sup>11</sup>; Casa Nova (BA), Petrolina (PE) and Remanso (BA)<sup>12</sup>; Belo Horizonte (MG)<sup>15</sup>. Two articles were published in 2007, three in 2016, and one in 2017.

Table 1. Sociodemographic data in the articles selected

Article	Year of publication	Location	Sample	Average age	Schooling level	Type of stroke	Gender	Marital status	Household income
Facing and reframing the stroke: perception of the elderly served in health care network <sup>4</sup>	2016	Centro Catarinense de Reabilitação – Florianópolis (SC)	9 older adults	72 years	6.1 years	Ischemic	Mostly men	Mostly married	From R\$788 to R\$3,000
Survivors' perspective of life after stroke <sup>5</sup>	2016	Inland Northeast	8	54 years	<1 year	Not present	3M 5W	Mostly married with children	From 1 to 2 minimum wages
Rehabilitation process experience after a cerebral vascular accident: a qualitative study <sup>10</sup>	2007	Serviço de Neurologia – Sobral (CE)	12	61 to 80 years	5 years, incomplete high school	Not present	7M 5W	4 married	1 minimum wage, 3–5.3 minimum wages
Dealing with losses: the perception of disabled patients after stroke <sup>1</sup>	2007	Ijuí (RS)	6	66 years	Incomplete elementary school	Not present	4M 2W	Married	Retirees
Therapeutic itineraries for patients with cerebrovascular accident: fragmentation of care in a regionalized health network <sup>2</sup>	2017	Casa Nova (BA) Juazeiro (BA) Petrolina (PE) Remanso (BA)	16	From 36 to 82 years	Not present	Not present	9M 7W	Not informed	Not informed
Therapeutic itineraries of men affected by encephalic vascular accident <sup>15</sup>	2016	Belo Horizonte (MG)	14	From 39 to 89 years	Not present	2 hemorrhagic, 12 ischemic	14M	Not informed	8 at workforce age, 6 retired

W: women; M: men

Data saturation was the method described for sample closure. Semi-structured interviews were conducted. One study did not present the instrument used for data collection<sup>13</sup>. Patients were interviewed in their households or hospital facilities. The guiding question was described in only two articles. As for the

analysis method, three reported using content analysis: one used what was called as “an interpretive analysis of the disease experience,” one did not clarify the data analysis method, and the other failed to describe it. Table 2 shows that all articles used different analytical categories, except for one<sup>13</sup>.

Table 2. Studies characteristics

Article	Sampling	Type of interview	Interview location	Data analysis	Guiding question	Category
Facing and reframing the stroke: perception of the elderly served in health care network <sup>4</sup>	Data saturation	Semi-structured	Home and rehabilitation center	Thematic content analysis, according to Minayo	Not present	1 Facing the stroke; 1.1 Recognizing the stroke; 1.2 Feeling the disease; 1.3 Meaning the cause of having a stroke; 1.4 Expectations regarding recovery from the stroke. 2 Resignifying life after stroke; 2.1 Changing after the stroke; 2.2 Living after the stroke; 2.3 Searching for strategies to cope with the stroke.
Survivors' perspective of life after stroke <sup>5</sup>	Not present	Not present	Home	Not present	What happened to you the day of the stroke? How did you feel about this experience? What helps you face this process? How did your life look after the stroke?	Not present
Rehabilitation process experience after a cerebral vascular accident: a qualitative study <sup>6</sup>	Saturation	Semi-structured	Home	Interpretive analysis of the disease experience	Not present	1 The rehabilitation process after stroke is permeated by difficulties; 2 The rehabilitation process is restricted to the follow-up of physicians at the health center; 3 The family as a support of the rehabilitation process; and 4 The rehabilitation process determines changes in lifestyle.
Dealing with losses: the perception of disabled patients after stroke <sup>11</sup>	Snowball	Semi-structured	Home	Content analysis, thematic modality, following steps proposed by Minayo	Open question: "What has your life been like after the stroke?"	Dealing with losses regarding independence, autonomy, identity, self-esteem, and affectivity.
Therapeutic itineraries for patients with cerebrovascular accident: fragmentation of care in a regionalized health network <sup>2</sup>	Not present	Semi-structured	Home	In-depth content analysis	Not present	Primary Health Care and the care received before the stroke; the path taken at the time of emergency; hospitalization; care received after discharge; the family role in care management; and the public-private association in access to health services.
Therapeutic itineraries of men affected by encephalic vascular accident <sup>15</sup>	Not present	Semi-structured	Home	Thematic content analysis	Not present	The onset of the disease; men and their care network; and therapeutic itineraries.

## Characterization of the subjects included in the studies

The average age of the subjects who participated in the studies was 63 years, mostly males, married, with low schooling level, and with an approximate income ranging from 1 to 2 minimum wages.

About the prevalence of stroke in Brazil, Bensenor et al.<sup>3</sup> presents the following: 1.6% in men and 1.4% in women; disability in 29.5% and 21.5% among men and women, respectively; high prevalence rates, especially in older adults with no formal education. These data corroborate the findings of our review.

## DISCUSSION

All these articles addressed the rehabilitation process, specially the article by Caetano et al.<sup>10</sup>, in which they clarify the importance of the integrality of care, emphasizing the role of physical therapy, which, according to them, is not always within everyone's reach. Based on the patients' perspective, the findings indicate that drug treatment may be enough for some, and that physical therapy is difficult because they rely on transportation or family members to accompany them, in addition to the fact that public services are centralized, making it difficult to access.

We emphasize that comprehensive rehabilitation does not involve only physical therapy services and that the needs of each patient must be individually analyzed. However, stroke sequelae are most often related to motor impairments, and physical therapy is fundamental to the process of functional recovery.

In Brazil, an ordinance published by the Ministry of Health in 2012 regulated the stroke care strategy, aiming to provide integrated care for these patients, such as universal access to the therapies established in guidelines, while respecting regional differences<sup>16</sup>.

Silva et al.<sup>13</sup> indicate that the offer of physical therapy services by the Brazilian Unified Health System (SUS) is still insufficient, requiring more investments, whether by hiring human resources, expanding the service network, or providing adequate transportation for users.

Individuals who suffered a stroke presented dissatisfaction regarding the access to interventions after hospital discharge, they mention restrictions for continuity of care in the community scenario<sup>1</sup>. The findings show a dissociation between public policy guidelines for the care and rehabilitation of stroke

survivors and the reality experienced by these people and their families. Spedo, Pinto, and Tanaka<sup>17</sup> show that the access to specialized services—among them rehabilitation—has been considered one of the main obstacles to the effectiveness of the integrality of SUS.

One of the conclusions of Girardon-Perlini and Faro<sup>18</sup> is that the way each person faces illness and the limitations resulting from it, relates to individual characteristics and the meanings given to the event, as well as the support and encouragement received from the family, the possibility of access to health resources and to professionals who—besides valuing subjective issues—guide and help in recovery, in coping, and/or in adapting to the lost functions.

According to Girondi et al.<sup>14</sup>, the process of falling ill is unique: each affected person has their way of acting, feeling, and signifying the disease, influencing their rehabilitation process. The authors emphasize the role of family and healthcare professionals as motivators in the recovery and coping with the disease by older adults affected by stroke. In this process, a structured health network is indispensable to provide continuous and integral care.

Marques et al.<sup>19</sup> emphasize that family and cultural values play an essential role in the rehabilitation process of stroke patients. However, Bocchi<sup>20</sup> highlights that, for family members to be able to provide this care, is necessary to offer adequate conditions and information about the disease while also offering emotional support to cope with this new condition.

For Amaral et al.<sup>21</sup>, family is a nucleus of forces that can interfere in the health-illness process of individuals, with consequences for the overall rehabilitation process and social reintegration.

The study by Fausto et al.<sup>12</sup> observed a lack of adequate orientation at discharge: the referral from the hospital service to the primary health care service did not happen formally. They also mention that the discharge report was sometimes unavailable to the patient, who did not receive explanations on what was being requested.

Although referred for follow-up with a neurologist, cardiologist, and physical therapist, in most cases the patient lacked access to such services, probably because the referral made by the hospital was more a "recommendation" than a guaranteed access to it.

Castro et al.<sup>15</sup>, in a qualitative study conducted with hospitalized men, concluded that the therapeutic itinerary—from the beginning to hospital discharge—is very autonomous for men, and that such logic is caused by social aspects of masculinity, such as being strong, inflexible, unwavering, and provider.



All articles highlight the importance of integrality of care, as well as the role of the family, which is essential for the recovery process. They also stress that the lack of guidance for patients and caregivers by health professionals can be a limiting factor to accessing therapies and adhering to the treatment. The caregivers play a very important role in this process: when well oriented, they become facilitators of the rehabilitation process.

## CONCLUSION

This review synthesizes the knowledge produced, within the intended scope, about the rehabilitation itinerary of stroke patients, presenting obstacles and evidencing the scarcity of studies on the subject in Brazil.

These studies highlighted the importance of integrality of care, the role of the family in the recovery process, the centralization of services, the difficulty with transportation, and the unavailability of family members and caregivers as obstacles in the rehabilitation itinerary. Such results reinforce the need to improve the care pathway of the stroke patient and the demand for integrality in their care.

Future investigations that collaborate to understand the process of stroke care, especially from the perspective of those affected regarding access to services, can potentially help management, in accordance with stroke care strategy for a more comprehensive rehabilitation, as recommended by the SUS.

## REFERENCES

- Organização Pan-Americana da Saúde. OMS revela principais causas de morte e incapacidade em todo o mundo entre 2000 e 2019. Genebra: Opas; 2020. Available from: <https://www.paho.org/pt/noticias/9-12-2020-oms-revela-principais-causas-morte-e-incapacidade-em-todo-mundo-entre-2000-e>
- Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. Diretrizes de atenção à reabilitação da pessoa com acidente vascular cerebral. Brasília (DF): Ministério da Saúde; 2013 [cited 2022 Nov 10]. Available from: [http://bvsm.sau.gov.br/bvs/publicacoes/diretrizes\\_atencao\\_reabilitacao\\_acidente\\_vascular\\_cerebral.pdf](http://bvsm.sau.gov.br/bvs/publicacoes/diretrizes_atencao_reabilitacao_acidente_vascular_cerebral.pdf)
- Bensenor IM, Goulart AC, Szwarcwald CL, Vieira MLFP, Malta DC. Prevalence of stroke and associated disability in Brazil: National Health Survey – 2013. *Arq Neuropsiquiatr*. 2015;73(9):746-50. doi: 10.1590/0004-282X20150115.
- Beckett J, Barley J, Ellis C. Patient perspectives of barriers and facilitators of treatment-seeking behaviors for stroke care. *J Neurosci Nurs*. 2015;47(3):154-9. doi: 10.1097/JNN.000000000000134.
- Ellis-Hill C, Robison J, Wiles R, McPherson K, Hyndman D, et al. Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke. *Disabil Rehabil*. 2009;31(2):61-72. doi: 10.1080/09638280701775289.
- Martinsen R, Kirkevold M, Svein U. Young and midlife stroke survivors' experiences with the health services and long-term follow-up needs. *J Neurosci Nurs*. 2015;47(1):27-35. doi: 10.1097/JNN.000000000000107.
- Sanches RCN, Figueiredo FSF, Rêgo AS, Decesaro MN, Salci MA. Itinerários terapêuticos de pessoas com doença renal crônica e suas famílias. *Cienc Cuid Saude*. 2016;15(4):708-15 doi: 10.4025/cienccuidsaude.v15i4.34529.
- Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. *Texto Contexto Enferm*. 2008;17(4):758-64. doi: 10.1590/S0104-07072008000400018.
- Souza MT, Silva MD, Carvalho R. Revisão integrativa: o que é e como fazer. *Einstein (Sao Paulo)*. 2010;8(1 Pt 1):102-6. doi: 10.1590/S1679-45082010RW1134.
- Caetano JA, Damasceno MMC, Soares E, Fialho AVM. A vivência do processo de reabilitação após acidente vascular cerebral: um estudo qualitativo. *Online Braz J Nurs*. 2007;6(2). doi: 10.17665/1676-4285.2007801.
- Girardon-Perlini NMO, Hoffmann JM, Piccoli DG, Bertoldo C. Lidando com perdas: percepção de pessoas incapacitadas por AVC. *REME Rev Min Enferm*. 2007;11(2):149-54.
- Fausto MCR, Campos EMS, Almeida PF, Medina MG, Giovannella L, et al. Itinerários terapêuticos de pacientes com acidente vascular encefálico: fragmentação do cuidado em uma rede regionalizada de saúde. *Rev Bras Saude Mater Infant*. 2017;17(Suppl 1):S63-72. doi: 10.1590/1806-9304201700s100004.
- Silva JK, Vila VSC, Ribeiro MFM, Vandenberghe L. A vida após o acidente vascular cerebral na perspectiva dos sobreviventes. *Rev Eletron Enferm*. 2016;18:e1148. doi: 10.5216/ree.v18.34620.
- Girondi JBR, Schier J, Hammerschimid KSA, Bento RR, Souza LP, et al. Enfrentando e ressignificando o acidente vascular cerebral: percepção de idosos atendidos na rede de atenção à saúde. *Rev Kairos*. 2016;19(1):317-38. doi: 10.23925/2176-901X.2016v19i1p317-38.
- Castro MA, Silva KL, Marques RC. Itinerários terapêuticos de homens acometidos por acidente vascular encefálico. *Rev Enferm UFPE On Line*. 2016;10(7):2488-95. doi: 10.5205/1981-8963-v10i7a11306p2488-2495-2016.
- Brasil. Ministério da Saúde. Linha de cuidados em acidente vascular cerebral (AVC) na Rede de Atenção às Urgências e Emergências. Brasília (DF): Ministério da Saúde; 2012.
- Spedo SM, Pinto NRS, Tanaka OY. O difícil acesso a serviços de média complexidade do SUS: o caso da cidade de São Paulo, Brasil. *Physis*. 2010;20(3):953-72. doi: 10.1590/S0103-73312010000300014.
- Girardon-Perlini NMO, Faro ACM. Cuidar de pessoa incapacitada por acidente vascular cerebral no domicílio: o fazer do cuidador familiar. *Rev Esc Enferm USP*. 2005;39(2):154-63. doi: 10.1590/S0080-62342005000200005.
- Marques S, Rodrigues RAP, Kusumota L. Cerebrovascular accident in the aged: changes in family relations. *Rev Lat*

- Am Enfermagem. 2006;14(3):364-71.doi: 10.1590/S0104-11692006000300009.
20. Bocchi SCM. O papel do enfermeiro como educador junto a cuidadores familiares de pessoas com AVC. Rev Bras Enferm. 2004;57(5):569-73.doi: 10.1590/S0034-71672004000500011.
21. Amaral NN, Cunha MCB, Labronici RHDD, Oliveira ASB, Gabbai AA. Assistência Domiciliar à Saúde (Home Health Care): sua história e sua relevância para o Sistema de Saúde atual. Rev Neurocienc. 2001;9(3):111-7. doi: 10.34024/rnc.2001.v9.8914.