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Review article

The needs of informal caregivers caring for stroke patients in the home environment

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Abstract
Background: Stroke is the leading cause of disability, impacting both the affected person and informal caregivers. As the number of stroke patients rises, it is increasingly important to recognize that informal stroke caregivers have needs that require support and interventions.
Objectives: The aim was to create an overview of studies where informal caregivers express their specific needs related to providing care for stroke patients in the home environment and summarize the described needs into particular categories.
Methods: A review of the literature published between 2013–2023 was conducted using the PRISMA methodology. The search for relevant articles used electronic databases Web of Science, Scopus, and PubMed. 21 articles met the entry criteria.
Results: Our analysis revealed 10 domains of needs of informal caregivers taking care of stroke patients in the home environment: the need to obtain information, the need to learn the life aspects of the patient after stroke, the need for a new family dynamic, the need to manage practical matters/non-care tasks, the need to communicate with the patient, the need for closeness, the need for physical health, the need for mental health, social needs, and the need for formal and informal support.
Conclusion: The burden on informal caregivers has been confirmed by a wealth of research, including this study. As challenges faced by stroke patients and their caregivers evolve, their needs must be regularly reviewed to ensure appropriate interventions, treatments, and support to improve overall care after a stroke.

Keywords: Home environment; Informal caregiver; Needs; Stroke

Introduction

A stroke or sudden damage to brain function due to vascular dysfunction often leads to permanent loss of speech, mobility, and memory. In the European Union (EU), stroke is the second leading cause of death and the leading cause of adult disability (Wilkins et al., 2017). In 2017, there were 1.12 million strokes recorded in the European Union, and there are 9.53 million stroke survivors (Wafa et al., 2020). The number of stroke survivors living in the EU is predicted to increase by 27% by 2047 due to population aging and high levels of acute healthcare (Wafa et al., 2020). Successful stroke recovery depends on four factors: the extent of damage, the skills of rehabilitation specialists, the support and cooperation of family and friends, and rehabilitation timing. According to the National Institute of Neurological Disorders and Stroke in the USA, care by family and friends is one of the most crucial factors in a stroke patient's recovery (Brandon, 2013).

Although a stroke can occur at any age, it most commonly occurs in people over 60, with caregivers in home environments usually around the same age (Camak, 2015). Different definitions of home caregivers emerge in various stroke studies. Home caregivers are generally informal, unpaid, and the primary caregivers. Stroke often causes long-term disability in patients and significant changes in the lives of their home caregivers. Informal caregivers provide both physical and emotional support and thus play a key role in patient adaptation to their disability and in achieving the maximum possible functional potential of the patient. The role of the caregiver is usually entrusted to family members, friends, or other close persons, but this role usually falls to the spouse or partner of the patient. The average time spent caring for a person with a stroke is approximately 41 hours per week (Denham et al., 2018).

Stroke and subsequent damage are not only stressful for stroke patients but also for their caregivers. After a stroke, providing round-the-clock care for a loved one often includes addressing behavioral disorders, communication, memory deficiencies, and physical support. The stress associated with home care can overwhelm the caregiver and negatively impact both caregivers' and patients' emotional, social, psycholo-

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gical, and physical health. According to the Family Caregiver Alliance (USA), "Family caregivers experience high rates of depression, stress, and other mental health problems" (Camak, 2015). As the number of stroke patients rises, it is increasingly important to recognize that informal stroke caregivers need constant support. To be effective, the support should respond to the current needs of informal caregivers. The aim of this research was to create an overview of studies on specific needs of informal caregivers providing home care to stroke patients.

Materials and methods

The aim was to create an overview of studies where informal caregivers express their specific needs related to providing care for stroke patients in the home environment and summarize the described needs into particular categories.

Study design

For the selection of suitable studies and subsequent data collection, research with elements of systemization using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology was chosen (Page et al., 2021). The research was conducted in January 2023. The search used bibliographic and multidisciplinary electronic databases, Web of Science, Scopus, and PubMed. Studies published from 2013 to 2023 inclusive are incorporated into the work. Only studies that met the selection criteria and were fully available were included in the research.

Search strategy and selection criteria

Criteria for inclusion in the analysis: (1) English and Czech professional periodicals published in 2013–2023, (2) target audience – adult population, and (3) research area – social sciences, psychology, health care, rehabilitation, clinical neurology. The search strategy combined the following terms: "needs", "caregiver", "caregiving", "stroke", and the Boolean operators AND/OR as follows: (1) needs AND caregiver AND stroke, (2) needs AND caregiving AND stroke, (3) needs AND caregiver OR caregiving AND stroke. All resultant sources were checked for relevant content based on the title and abstract. Duplicate sources, irrelevant titles, protocols, proceedings records, editorials, commentaries, and case studies were discarded.

Since this research is focused on the needs of informal caregivers caring for stroke patients in the home environment, all studies dealing with the needs of patients, the needs of patients from the perspective of caregivers, the needs of caregivers relative to patients in institutional care or transition to a home environment, studies assessing the relationship between patients and caregivers, studies evaluating the quality of life without a description of the caregiver's needs, studies that did not specify which type of patient was being cared for, and studies evaluating the effect of interventions were excluded. Based on keyword searches and relevant studies in reference lists, 766 sources were found and further classified according to the PRISMA scheme (Diagram 1). The final review study included 21 articles that met the entry criteria.

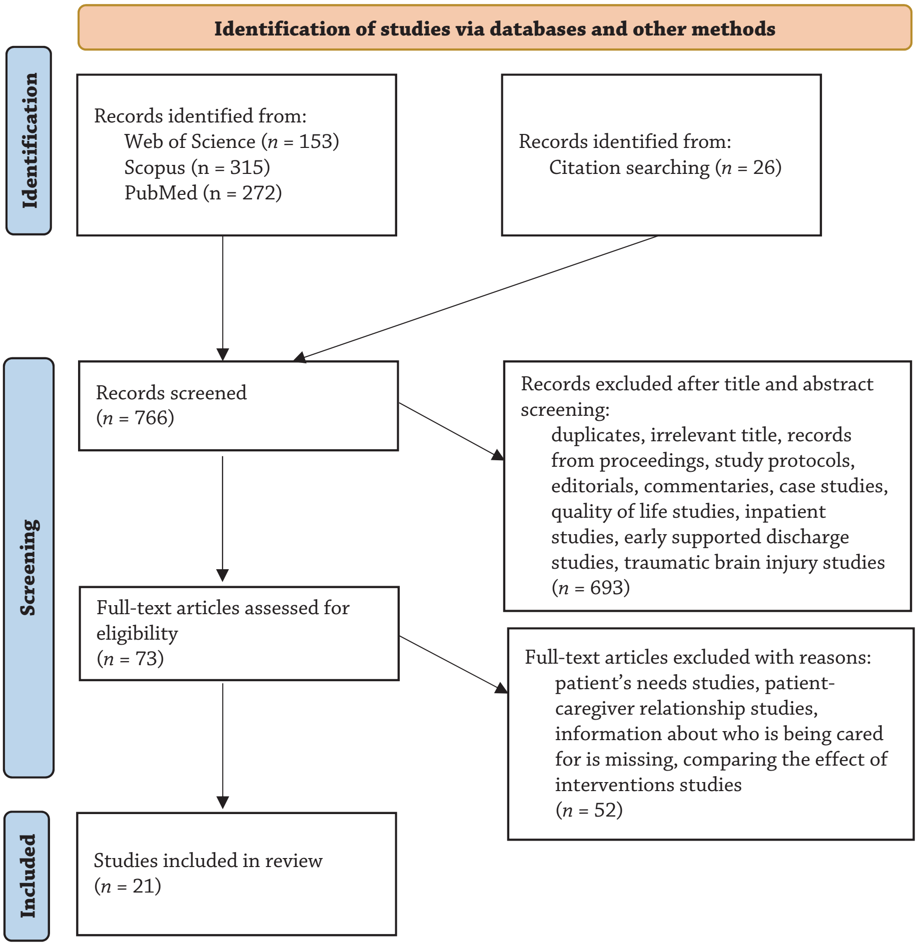

Diagram 1. PRISMA 2020 flow diagram for new systematic reviews (Page et al., 2021)

Data extraction

All selected publications were saved for data extraction. The data collected included the author's name, year, country, goals, population studied (number of participants, gender, kinship, and time since stroke), study design, type of analysis, and conclusions in the form of domains/categories of informal caregivers' needs.

Data synthesis

The data synthesis for this review was based on a systematic narrative approach due to the heterogeneity of the studies included, *i.e.*, differences in design and type of studies.

Results

Selection of studies

The studies were selected based on the PRISMA methodology, as shown in Diagram 1. Twenty-one scientific papers were selected for synthesis and extraction (summarized in Suppl. 1).

Study characteristics

Most research studies were conducted in Europe (*n* = 8) and Asia (*n* = 7). Another four studies come from America, and two from Australia. The tools used to capture the needs of informal caregivers were most commonly different types of interviews and questionnaires. Needs were examined in different time periods after a stroke, no earlier than two weeks after the patient's discharge from the hospital and no later than 28 years after the stroke. In the analyzed studies, informal caregivers were mostly women, often spouses or partners. The average age of the caregiver, if reported, was 53.4 years.

Reported specific needs

1. *The need to obtain information*

Caregivers reported receiving inadequate information; the missing information can be divided into the following categories:

- Stroke-related information:
  - what is included in comprehensive care (Sidek et al., 2022);
  - what is timely and individualized care, transition to a home environment, seeking help and support (Stiekema et al., 2020);
  - warning signs of another stroke, how lifestyle changes, where to look for resources, how to manage specific problems or complications, what to expect, stroke risk factors, and comprehensive care/rehabilitation options (Bakas et al., 2016; Cecil et al., 2013; Denham et al., 2020; Tsai et al., 2015);
  - how to manage sudden and unexpected events (Holloway, 2019; Tsai et al., 2015);
  - information about diagnosis and treatment options (Li et al., 2017);
  - need for education and information about stroke (Sidek et al., 2022);
  - information about death and dying (Denham et al., 2020).
- Information about services:
  - access to health services, coordination and continuity of physical and emotional care, appropriateness and clarity of the information provided (Denham et al., 2020);
  - obtaining adequate information and access to health services (Denham et al., 2019; Farahani et al., 2020);
  - the possibility of meeting and sharing/comparing with other informal caregivers (Geard et al., 2020);
  - information on required equipment (Batuecas-Caletrío and Rodríguez-Martín, 2022).

2. *The need to manage vital aspects of the patient's life after a stroke*
   - coping with the patient's emotions and behavior, personality changes, cognition, communication, and social activities (Bakas et al., 2016);
   - worrying about the patient (Cecil et al., 2013);
   - how to provide emotional and psychological support to the patient (Denham et al., 2020; Farahani et al., 2020);
   - patient behavior is a challenge – loss of identity, complicated grief, questioning the meaning of life (Holloway, 2019);
   - how to provide care according to the patient's needs (Lu et al., 2022).

3. *The need for a new family dynamic*
   - changing household roles and related tasks, finding a balance between caregiver duties and one's own needs (Bakas et al., 2016; Batuecas-Caletrío and Rodríguez-Martín, 2022; Denham et al., 2020; Lu et al., 2022);
   - dual responsibility, concern for the future and family, long care periods, and minimal free time (Tiwari et al., 2021);
   - more household responsibilities (Rahman et al., 2018);
   - lifestyle changes (Cecil et al., 2013; Tiwari et al., 2021);
   - adaptation to changes, awareness of consequences, the process of acceptance, dealing with the consequences in everyday life, personal time, changing roles in the relationship and family (Stiekema et al., 2020);
   - coping with uncertainties and life after stroke, finding meaning for oneself and the patient (Denham et al., 2020);
   - closeness in family life (Fugl-Meyer et al., 2019);
   - balancing family needs and personal autonomy, creating space for one's own needs (Geard et al., 2020);
   - existing and new family roles in the context of stroke, unavoidable duty (Holloway et al., 2019);
   - intensity of care described as "care and nothing more", no life horizons, inability to leave the role of caregiver (López-Espuela et al., 2018).

4. *Need to manage practical matters/non-care tasks*
   - financial security, legal health services, transport, respite care (Bakas et al., 2016; Denham et al., 2020);
   - financial support (Li et al., 2017; Lu et al., 2022);
   - financial needs – food, education, transportation (Pesantes et al., 2017; Rahman et al., 2018),
   - fighting for services (Holloway et al., 2019);
   - proactive coping with situations (Kruithof et al., 2016);
   - financial burden (Tiwari et al., 2021).

5. *The need for communication with the patient*
   - communicate needs, concerns, and mutual relationships (Bakas et al., 2016; Batuecas-Caletrío and Rodríguez-Martín, 2022; Cecil et al., 2013; Denham et al. 2020);
   - have a satisfactory relationship with loved ones and communicate with them (Denham et al., 2020; Kruithof et al., 2016);
   - communication with the patient (Mumma, 2020).

6. *The need for proximity*
    - restoring physical intimacy and sexual needs (Denham et al., 2020);
    - close partner relationship and sex life (Fugl-Meyer et al., 2019);
    - maintaining closeness and togetherness, defining new sexuality and intimacy, lack of resources and communication with experts in this field (Kniepmann and Kerr, 2018);
    - restoring partner life, often described as a "broken relationship" (López-Espuela et al., 2018).

7. *The need for physical health*
    - need for physical health (Cecil et al., 2013);
    - lack of energy (Bakas et al., 2016);
    - fatigue, headaches, muscle overload (Batuecas-Caletrío and Rodríguez-Martín, 2022; Pesantes et al., 2017);
    - having time for yourself (Denham et al., 2019; Rahman et al., 2018);
    - overload (Kruithof et al., 2016; Tiwari et al., 2021);
    - sleep disorders, forgetfulness (Rahman et al., 2018).

8. *The need for mental health*
    - need for emotional and psychological balance, coping with emotions (Bakas et al., 2016; Lu et al., 2022);
    - incredulity, irritability, anxiety, resignation (Batuecas-Caletrío and Rodríguez-Martín, 2022);
    - emotional irritability (Rahman et al., 2018);
    - psychological problems (Cecil et al., 2013);
    - anxiety and tension (Tiwari et al., 2021);
    - anxiety and depressive symptoms (Kruithof et al., 2016);
    - depressive symptoms – sadness, extreme sensitivity, difficulty sleeping, lack of motivation, suicidal thoughts, need to visit a psychologist (Pesantes et al., 2017);
    - how to manage emotional needs (Lu et al., 2022);
    - mental well-being, gratitude, faith, and hope for the future (Cecil et al., 2013; Denham et al., 2020);
    - emotional distress, emotional support (Denham et al., 2020; Farahani et al., 2020);
    - having time for oneself (Denham et al., 2019, Rahman et al., 2018);
    - need for independence (Mumma, 2020);
    - maintaining a positive outlook (Geard et al., 2020; Holloway et al., 2019);
    - finding internal strength and taking control of the situation through meaningful behavior (Geard et al., 2020);
    - unpredictability of the future, loss of identity, personal sacrifice (Holloway et al., 2019);
    - self-confidence in one's abilities (Kruithof et al., 2016).

9. *Social needs*
    - social activities (Bakas et al., 2016);
    - activities, travel, social life (Mumma, 2020);
    - having someone to talk to (Denham et al., 2020);
    - lack of independence and time for social activities – meeting friends or visiting relatives (Pesantes et al., 2017);
    - disrupted social life (Tiwari et al., 2021);
    - lack of time with friends, inability to attend family events (Rahman et al., 2018);
    - impact on employment and lifestyle (Denham et al., 2020);
    - the need to pursue employment (Rahman et al., 2018; Tiwari et al., 2021);
    - social relationships and support (Denham et al., 2019);
    - advice from professionals in the community network domain (Farahani et al., 2020; Tsai et al., 2015);
    - motivating oneself through relationships (Geard et al., 2020);
    - daily social support (Kruithof et al., 2016; Li et al., 2017);
    - loneliness in care, going through everything alone (López-Espuela et al., 2018);
    - getting understanding from relatives/friends, professionals, institutions, and society (Stiekema et al., 2020).

10. *Need for formal and informal support*
    - need for help (Bakas et al., 2016);
    - family support, help from caregivers caring for similar patients, professional support (Batuecas-Caletrío and Rodríguez-Martín, 2022; Cecil et al., 2013; Farahani et al., 2020; Stiekema et al., 2020);
    - case management (Stiekema et al., 2020);
    - help in caring for one's own mental and physical health, spiritual support, help with ADL, and coping with the caregiver role (Denham et al., 2020);
    - necessary but troubling need for professional help (Geard et al., 2020);
    - dependence on family support and assistance, professionals exclude family, have expertise, lack empathic understanding and humanity, practical help and "presence", recognition of insecurity, and flexible approach from professionals (Holloway et al., 2019);
    - financial and social support (Li et al., 2017);
    - the need to visit a psychologist (Pesantes et al., 2017);
    - psychological support for caregivers (Sidek et al., 2022).

Research has shown that most of the needs of caregivers are related to support for the post-stroke patient. However, caregivers also report several life-oriented needs. The described domains of needs are intertwined and interconnected. The need for social activities can be perceived in an opposing relationship with the need to learn the life aspects of the patient after stroke, manage practical matters/non-care tasks, and the need for a new family dynamic. The need for social activities takes a backseat to these needs, because the caregiver takes care of the patient, the household, secures finances, and only then has time for his own activities. However, due to the care provided, he has a shortage of this free time. To ensure family dynamics, practical matters, finances, physical health and their own social activities, the caregiver needs formal and informal help and support. Social needs, mental health, proximity, and the need to communicate with the patient are closely linked. But even for their satisfaction, the other described needs must be provided.

Discussion

This review study summarizes the needs of informal caregivers caring for stroke patients at home. It aims to provide a list of described needs without emphasizing the relative importance of these needs. Our analysis revealed ten domains of needs: the need to obtain information, including information related to stroke and information about services, the need to learn the life aspects of the patient after stroke, the need for a new family dynamic, the need to manage practical matters/non-care tasks, the need to communicate with the patient, the need for proximity, the need for physical health, the need for mental health, social needs, and the need for formal and informal support.

The need to obtain information

The responsibility for caring for a loved one who has suffered a stroke is enormous and complicated. Families and friends are thrown into the role of caregiver within hours. They do not know how to learn new skills, which leads to uncertainty and confusion. Most caregivers are not prepared to face the challenges of this new role due to the sudden onset of strokes and the extensive care patients need after a stroke. While it is often natural to view informal caregivers as members of the patient's interprofessional care team, it is essential to remember that they, too, have needs that require support and interventions. Research has shown that a lack of stroke-related information, as well as information about available services, is one of the most commonly cited factors contributing to caregiver overload. A study by Creasy et al. (2013) found that some caregivers felt separated and ignored by healthcare providers and were unable to successfully meet their significantly increased need for information. A study by Greenwood et al. (2010) showed that 87% of caregivers felt they needed more information about strokes, the likelihood of another stroke, information related to their loved one's specific individual symptoms, and their needs after a stroke regarding social or financial services, and about care-related topics such as keeping a family member safe and finding time to care for themselves. Gaps in this area include a lack of educational programs that address the unique educational needs of caregivers, beginning with the admission of a stroke survivor (Camak, 2015).

The need to manage vital aspects of the patient's life after a stroke

Caregivers must learn how to help their loved one move, eat, dress, communicate, and perform other previously routine self-care tasks (Brandon, 2013). This creates the need to adapt to a new family dynamic and the need to get used to the new demands of patient care and learn new specialized skills. How well the caregiver copes with the new role depends on several variables, such as the patient's physical and cognitive impairments, the ability to cope with new situations, changes in relationships between family members, and the need for social support (Brandon, 2013). The greater the physical and cognitive damage to the patient, the greater the stress on the caregiver.

The need for a new family dynamic

Many informal caregivers have no experience and do not know how to care for a disabled or severely disabled person. However, they very often perform various tasks, some of which are comparable to those provided by professional caregivers. Moreover, caregivers must often take on other new responsibilities, such as household chores and family finances (Greenwood et al., 2009). Caregivers try to find a balance between caregiver duties and their own needs (Bakas et al., 2016). Due to the acute needs of patients who have suffered a stroke, many caregivers put patient needs over their own.

Need to manage practical matters/non-care tasks

Caregivers must also ask for help and support from others (Greenwood et al., 2010). These challenges can be overwhelming, especially for carers who lack financial and social resources. Informal care often leads to job interruptions and financial distress. The need for financial security thus generates another need for the family's help, as the caregiver is unable to handle the situation alone.

The need for communication with the patient

The ability to communicate is often impaired in the post-stroke patient. However, to maintain a satisfactory relationship it is important to communicate the needs of both partners. A study by Wolters et al. (2011) argues that caregivers who have a passive coping style involving isolation, fears about the past and future, and a focus on negative emotions are more prone to overload than those who have more assertive attitudes, behave proactively, communicate, ask for help, ask questions, and seek answers.

The need for proximity

Other research reports that informal caregivers express their needs, such as loneliness, suicidal ideation, *e.g.*, "being thrown off a cliff", exhaustion, going around in circles, insomnia, and loss of identity, closeness, and intimacy (King et al., 2010; Lutz et al., 2011; Pierce et al., 2012). A mutual effort to restore physical intimacy fosters closer partner relationships, which may influence all other needs. However, resources and communication with experts in this area are lacking (Kniepmann and Kerr, 2018).

Need for physical and mental health

Research has shown that being a long-term caregiver can affect a person's mental and physical health. Chronic health conditions such as hypertension, depression, and chronic obstructive pulmonary disease are more common among caregivers than those who are not caregivers (Brandon, 2013). Moreover, in one of the first studies to examine informal caregivers, Schulz and Beach (1999) found that caregivers providing long-term care at home had a 63% higher risk of death than non-carers. Pierce et al. (2012) described that as physical overload increases, caregivers feel fear and despair at the thought of another day as a caregiver. One caregiver reported that they "feel like they want to be hit by a truck" (Pierce et al., 2012).

Social needs

Gaps in this area include a lack of understanding of the importance of the informal caregiver role, and therefore, a low level of social interactions with the healthcare community, family and friends, as well as a lack of interventions to address the informal caregiver's burden. The demands of day-to-day care for stroke patients cause the caregiver to sacrifice all of their time and opportunities for social participation in the community.

Need for formal and informal support

Pierce et al. (2012) highlighted the need for social support services for caregivers, such as respite care and caregiver support organizations. This short-term relief is an important component to maintaining caregiver resilience and well-being (Kokorelias et al., 2020). The results of our review confirmed the need for formal and informal support and social contact. Gabura (2012) emphasizes that the family provides its members with the assurance that in difficult situations a person will not be alone and that other family members will share these situations with them. The caregiver needs to have the family close to them and be in contact with them.

In recent years, there has been an effort towards interprofessional patient care, but its practical implementation, especially for stroke patients in the home environment, is still insufficient. Given the identified needs of informal caregivers, especially obtaining information about services, help and support options, better communication between individual professionals and the affected family is needed. A possible solution is the position of a so-called case manager, which would be held by a social worker. In addition to cooperation with individual specialists, his task would be to provide information to patients and informal caregivers in a comprehensible and sensitive manner, to listen and ascertain current individual needs, to mediate contact with the necessary services, and to help the support system to be effective.

Research has revealed a lack of standards for the assessment of caregiver burden, interventions to assist caregivers, and follow up support for both caregivers and stroke patients. The results of our review of the needs of informal caregivers of stroke patients are intended to promote new interventions and services to meet the identified needs. These, in turn, could improve the preparedness of informal carers for their new caregiver role and help caregivers in all phases of the caregivers' experience. Further, our findings can improve the quality of life of caregivers by assisting them to manage their needs, maintain their mental, emotional, and physical health, and increase their ability to provide physical, emotional, and practical care for stroke patients. Our results could inform specialists who meet informal caregivers in an interprofessional team including neurologists, general practitioners, psychologists, physiotherapists, occupational therapists, speech therapists and others, about the specific needs of informal caregivers and lead to tailoring the support that informal caregivers need.

Conclusion

Stroke is the leading cause of disability, impacting the affected person as well as informal caregivers. Suddenly (and usually without warning), caregivers are thrown into a lifelong role as a caregiver to a stroke patient. Experts often focus on the needs of patients who have experienced a stroke without considering the needs of the caregiver, which are no less important. The burden on informal caregivers is confirmed by a wealth of research, including this study, which describes ten domains of needs of informal caregivers taking care of stroke patients in the home environment. As challenges faced by stroke patients and their caregivers evolve, their needs must be regularly reviewed to ensure appropriate interventions, treatments, and support to improve overall care after a stroke.

Study limitations

The needs of informal caregivers, as described in the examined studies, do not indicate how failure to meet these may affect the quality of care provided to the patient. This study also does not address the emergence of caregiver needs, interactions between these needs, and the short- and long-term consequences on the health of informal caregivers. It also does not take into account how these needs change over time after the patient's return to the home environment. These limitations provide an opportunity for further research in this area.

Ethical aspects and conflict of interest

The authors have no conflict of interest to declare.

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