

DEVELOPMENT OF A HANDBOOK FOR THE REHABILITATION OF POST-STROKE DYSPHAGIA AND COMMUNICATION DISORDERS

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ABSTRACT

Objective: Development of a handbook for the rehabilitation of post-stroke dysphagia and communication disorders.

Subjects and methods: Surveying the awareness and opinions of 20 post-stroke patients' caregivers at the Rehabilitation and Neurology department at Military Hospital 175 with self-design questionnaire. The handbook was written based on the Arizona State University Handbook Development and evaluated by experts before applying to the caregivers. After 1 week of use, the Patient Education Materials Assessment Tool was used to evaluate understandability, applicability and convenience by caregivers.

Results: 70% of caregivers agreed that stroke leaves many serious sequelae for the patient. 55% of caregivers agreed that the sequelae post-stroke, especially the sequelae of dysphagia and/or communication disorders, greatly affect the patient, caregivers, family, and society. 80% of relatives and caregivers are having difficulty understanding dysphagia, communication disorders post-stroke, and Speech & Language Therapy for rehabilitation post-stroke dysphagia and communication disorders. 70% of caregivers have difficulty finding information. 95% of caregivers need to be provided information by the handbook for the rehabilitation of dysphagia, and communication disorders post-stroke. The handbook was completed with 43 pages, evaluated by 06 Speech and Language therapists, 01 Rehabilitation doctor, 01 Neurologist and rated by caregivers

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for understandability at 98.2%, applicability and convenience at 100% according to the Patient Education Materials Assessment Tool.

Conclusion: Caregivers' need for communication disorders and dysphagia knowledge is urgent and understandable. Speech and Language therapy plays an important role in the rehabilitation of post-stroke dysphagia and communication disorders. In the context of a shortage of human resources in Speech and Language Therapy, the handbook should be widely applied in the Rehabilitation departments, Neurology departments, and nursing homes...

Keywords: handbook, communication disorders, dysphagia, post-stroke, Speech and Language Therapy, caregiver.

1. INTRODUCTION

Stroke is the leading cause of disability and the second leading cause of death worldwide according to WHO [1]. Communication disorders including communication disorders (CDs) and dysphagia occur in 30-60% of stroke patients, causing serious consequences such as depression, aspiration pneumonia and insomnia. malnutrition and prolonged hospital stay [2,3]. Speech and Language Therapy is an applied health profession, providing services and combining multi-specialties in the treatment of patients with CDs and dysphagia, the treatment process is coordinated with direct caregivers. In Vietnam, the demand for Speech and Language Therapy for patients after stroke is increasing significantly.

Lack of understanding and experience in caring for stroke patients can make CDs and dysphagia become more severe, affecting the physical, psychological and social health of both patients and

caregivers [4, 5]. Therefore, to increase understanding and minimize accidents and complications during the treatment and care of patients with CDs and/or dysphagia after stroke, the research “*Development of a handbook for the rehabilitation of post-stroke dysphagia and communication disorders*” was performed. In the context of a shortage of human resources in Speech and Language Therapy, the manual is a means of providing information about common mental disorders and mental disorders after stroke to raise the awareness of caregivers and help them have more information, knowledge and effective communication as well as basic care for dysphagia patients, assisting patients have early access to Speech and Language Therapy services.

2. SUBJECTS AND METHODS

2.1. Subjects

- ❖ Inclusion criteria:
 - Relatives and caregivers of

patients after stroke have communication disorders and/or dysphagia.

- Participants are over 18 years old.
- Patients’ relatives, caregivers agree to participate in study by signing consent form.

❖ Exclusion criteria:

- Participants have cognitive and visual problems.
- Illiterate people.

2.2. Method

❖ Study design: Description cross-sectional study.

❖ Sampling method: Convenience sampling.

❖ Data collection and analysis: Microsoft Excel and STATA version 16.0.

❖ Ethics: The study has been

approved by the Ethics Council of Military Hospital 175, No. 3152/HĐĐĐ dated August 18, 2023.

2.3. Research location

Rehabilitation and Neurology Department, Military Hospital 175.

2.4. Processes

❖ *Survey caregivers’ opinions before developing the handbook:* Surveyed 20 relatives and caregivers of post-stroke patients with CDs and/or dysphagia at the Rehabilitation and Neurology department, Military Hospital 175 using a self-developed 10-question questionnaire.

❖ *Handbook development process:* The handbook was developed according to the guidelines of Arizona State University, United States [6]. The process of creating a handbook includes 7 steps:

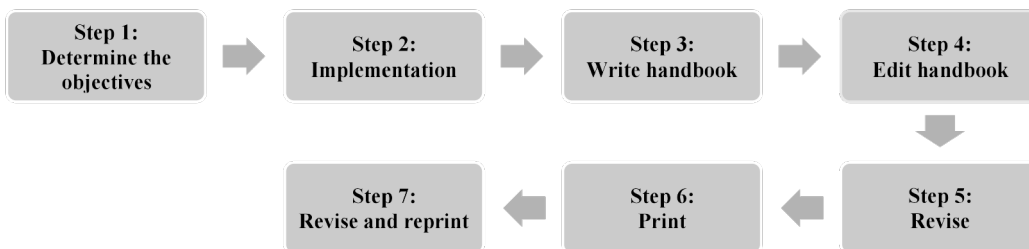


Figure 1: Flowchart of Arizona State University’s handbook development process (United States).

❖ *Evaluate before application:* The handbook was evaluated by 06 speech therapists, 01 rehabilitation doctor, 01 neurologist before being applied to caregivers.

❖ *Feedback on the handbook by users:* Randomly selected 10 patient caregivers to participate in the survey, to record comments and feedback on the comprehensibility, applicability and usability of handbook through the Patient Education Materials Assessment Tool - PEMAT, which includes 24 questions, after 1-week caregivers receive the handbook and use [7].

3. RESULTS

3.1. Results of the survey on awareness and opinions of patient caregivers before applying the handbook

3.1.1. Demographic characteristics

Table 1: Information about participants in the survey

Variables		Frequency	Percentages
Gender	Male	12	60%
	Female	8	40%
Age	18-60	18	90%
	> 60	2	10%
Academic level	High school	3	15%
	College	17	85%
Residence	Urban	15	75%
	Rural	5	25%

Caregivers’ awareness of stroke and the effects of communication disorders and dysphagia after stroke.

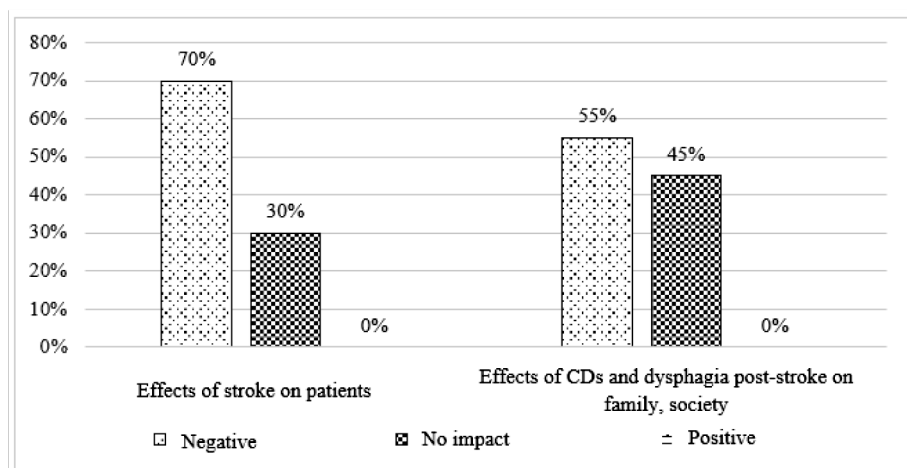


Figure 2: Survey results of feedback on stroke and the effects of CDs and dysphagia after stroke (n=20)

From the survey, 70% of caregivers said that stroke leaves many serious sequelae for the patient. 55% of caregivers said that the sequelae after a stroke, especially the sequelae of CDs and dysphagia, not only greatly affect the patient themselves but also affect caregivers, family and society.

3.1.3. The role of the caregiver for patients with communication disorders and/or dysphagia after stroke.

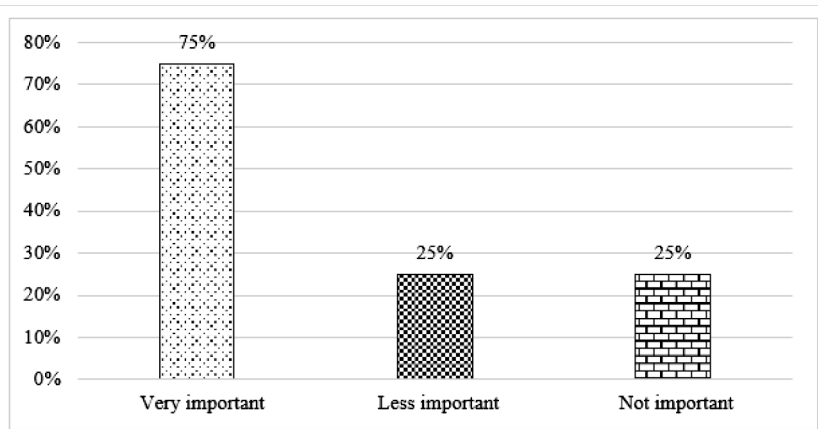


Figure 3: Survey results of opinion about the role of the caregiver for patients with communication disorders and/or dysphagia after stroke (n=20)

75% of caregivers think that they played a significantly important role in post-stroke patients, especially for post-stroke patients with CDs and/or dysphagia.

3.1.4. Difficulties of caregivers in taking care of patients with communication disorders and/or dysphagia after stroke.

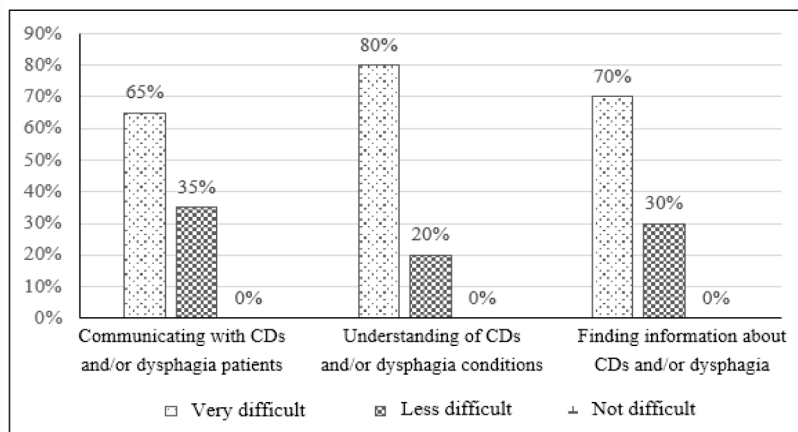


Figure 4. Survey results of difficulties of caregivers in taking care of patients with CDs and/or dysphagia after stroke (n=20)

65% of caregivers encountered many difficulties in communicating and taking care of patients with dysphagia and CDs. 80% of caregivers had a lot of difficulty understanding CDs and dysphagia after a stroke. 70% of caregivers faced many difficulties in finding information about CDs and dysphagia.

3.1.5. Caregivers’ perceptions of Speech and Language Therapy and challenges in accessing Speech and Language Therapy services.

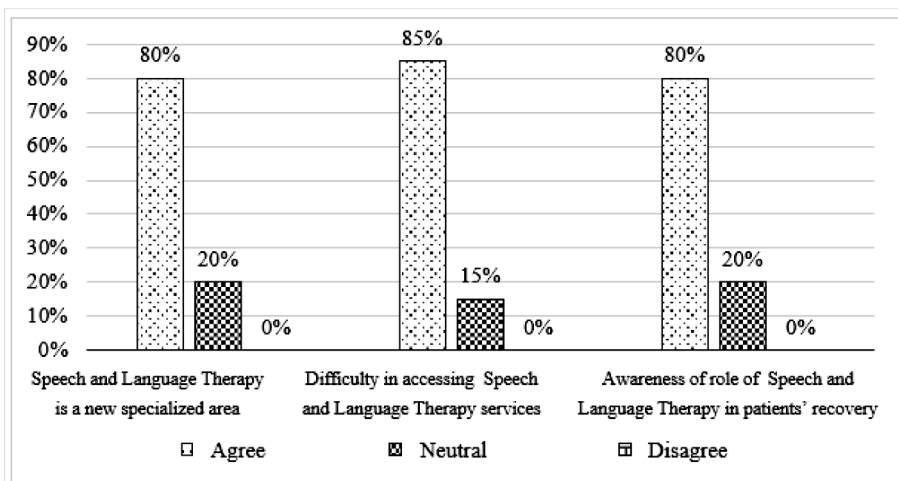


Figure 5: Survey results of caregivers’ perceptions of Speech and Language Therapy and challenges in accessing Speech and Language Therapy services (n=20)

80% of caregivers reported that Speech and Language Therapy is a relatively new specialty. After being informed about Speech and Language Therapy, 80% of caregivers believe that patients with CDs or dysphagia after a stroke should have access to these services. Additionally, 85% of participants mentioned that they struggled to find a medical facility offering Speech and Language Therapy services for patients with CDs and dysphagia post- stroke.

3.1.6. Needs should be informed through the handbook.

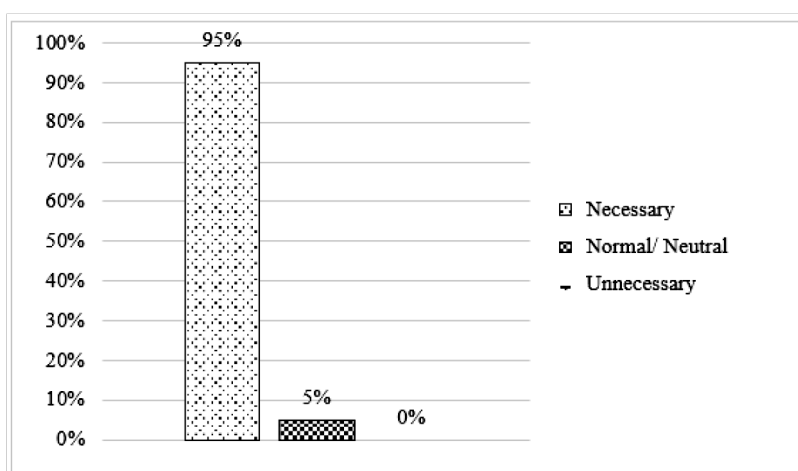


Figure 6: Survey results of needs should be informed through the handbook (n=20).

According to the survey, 95% of caregivers wanted to be provided with information through the *Handbook for the rehabilitation of post-stroke dysphagia and communication disorders*.

3.2. Handbook for the rehabilitation of post-stroke communication disorders and dysphagia.

- ❖ Product: a 43-page handbook.
- ❖ Handbook includes 4 items:
 - Information about stroke and its sequelae.
 - Information and instructions on common CDs after stroke include information on aphasia, dysarthria, CDs stemming from cognitive issues such as dementia following multiple strokes, including definitions, symptoms, precautions, and effective communication strategies with patients diagnosed with bipolar disorder.
 - Information and instructions on dysphagia post-stroke include information about the normal process, information about dysphagia, some common signs in dysphagia patients, basic instructions on safe eating, and oral hygiene..
 - Information about the role of Speech and Language Therapy in CDs and

dysphagia recovery after stroke and how to find Speech and Language Therapists, and where to provide Speech and Language Therapy services.

❖ Product characteristics:

- Handbook products are inherited from referenced handbook products and guidance documents [8,9].
- The product is new and complete: The product provides quite adequate information and instructions on common problems post-stroke patients need intervention in Speech and Language Therapy including CDs and dysphagia. The handbook product also provides information about the role of Speech and Language Therapy in recovering patients after stroke to relatives and caregivers of the patients and provides information on finding these services.

3.3. Evaluate the handbook before application.

Before distributing the handbook to caregivers, the handbook is evaluated by:

- ❖ 06 speech and language therapists.
- ❖ 01 rehabilitation doctor.
- ❖ 01 neurologist.

3.4. Evaluate the handbook from caregivers using the Patient Education Materials Assessment Tool - PEMAT.

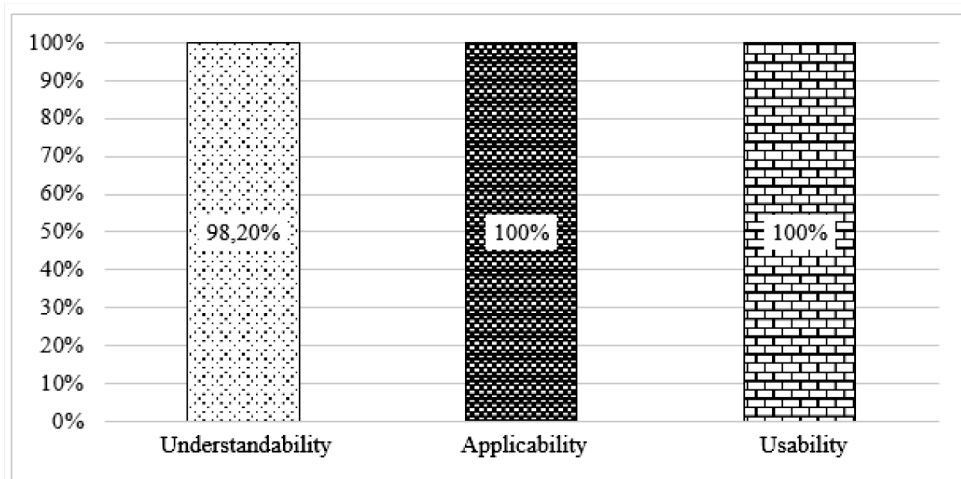


Figure 7: Result of evaluation of the handbook from caregivers (n=10)

The result showed that the handbook has 98.2% understandability, 100% applicability and 100% usability.

4. DISCUSSION

Stroke is becoming increasingly common among younger people and leaves many serious sequelae. Sequelae after stroke, especially CDs and/or dysphagia, not only greatly affect the patient himself but also affect the patient’s relatives, caregivers, family and society [10]. Post-stroke patients with CDs and dysphagia have difficulty expressing their needs, desires, and status to caregivers, medical staff, and other people around them. Also, they need supervision and support in eating safety and compliance from caregivers to prevent the risk of aspiration and aspiration pneumonia.

changes in life, especially changes in the roles and responsibilities of caregivers. Caregivers need to take on additional roles and responsibilities when caring for patients, especially patients with CDs and/or dysphagia [11]. The communication between caregivers and CD patients posed challenges for 65% of caregivers. The remaining 35% of caregivers encountered some difficulties as well, resorting to non-verbal communication such as gestures, nodding/shaking their head, and asking “Yes/No” questions. In some cases, they would speculate on the thoughts and actions of the patients, although these speculations were often incorrect. Additionally, patients often struggled to express their needs and feelings. Besides, caregivers have difficulty

Stroke often leads to sudden

understanding and often worry about the patient's dysphagia condition. They need a lot of time and effort to prepare special meals and care for people with dysphagia after stroke.

Caregivers have difficulty understanding the medical condition the patient is suffering from and the rehabilitation services that are available locally to support the patient [12]. There are 65% of caregivers do not know how to find information about CDs, dysphagia, Speech and Language Therapy services or they have searched on websites, but there are too many sources of information or information sources that provide information. appear inconsistent with many specialized words that confuse and make it even more difficult for caregivers to understand.

Speech and Language Therapy is an applied health industry, providing services, that combine multi-specialties in the treatment of patients with CDs and dysphagia. According to the survey, 80% of caregivers shared that "Speech and Language Therapy" was a new concept to them, they had never known about Speech and Language Therapy. When provided with information, 80% of caregivers agreed that patients with CDs and/or dysphagia need to have access to Speech and Language Therapy services after stroke, however, 85% of caregivers were having difficulty finding a medical facility

that offers this service.

Family members of patients with CDs set goals such as being involved in rehabilitation, receiving advice, explanations, encouragement, being able to communicate, and maintaining relationships with the person with CDs. Furthermore, caregivers also want support to help them acquire basic skills in caring for and encouraging patients after a stroke. In addition to verbal discussions and explanations, caregivers want to receive visual and written information about the patient's condition [13]. According to survey results, 95% of caregivers need to be provided with information through *Handbook for the rehabilitation of post-stroke communication disorders and dysphagia*. They want to be provided with information about the medical conditions that patients are suffering from, especially CDs, dysphagia and information about Speech and Language Therapy services.

Among the documents about the handbook development process, the guidance document of Arizona State University in the United States is a detailed, specific guidance process and a reliable source of documents for developing the *Handbook for the rehabilitation of post-stroke communication disorders and dysphagia*.

The handbook provides information about stroke, CDs, dysphagia and information about Speech and

Language Therapy in recovering CDs and dysphagia patients after stroke in a detailed and relatively complete way. The handbook is evaluated by experts in speech and language therapists, a rehabilitation doctor and a neurologist before being applied.

The handbook was rated by patient caregivers with 98.2% understandability and 100% applicability and usability according to the PEMAT scale.

5. CONCLUSION

Handbook for the rehabilitation of post-stroke communication disorders and dysphagia is quite comprehensive. It addresses issues that require Speech and Language Therapy intervention after a stroke, as well as the role of Speech and Language Therapy. It also provides support in finding information about

Speech and Language Therapy services for families and caregivers of patients with communication disorders and/or dysphagia after stroke.

The product is designed for relatives and caregivers with a high level of understanding, applicability, and usability, and can be easily applied. In the context of a shortage of human resources in Speech and Language Therapy, the handbook should be widely used in Rehabilitation, Neurology departments/units, and Nursing homes...

The survey and application of the handbook were carried out at the Rehabilitation and Neurology Department at Military Hospital 175. In the future, the handbook needs to continue to be tested for effectiveness with a survey larger sample size and continuously updated to ensure scientific and practical relevance.

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