

## A New Disability-related Health Care Needs Assessment Tool for Persons With Brain Disorders

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**Objectives:** This study aimed to develop a health needs assessment (HNA) tool for persons with brain disorders and to assess the unmet needs of persons with brain disorders using the developed tool.

**Methods:** The authors used consensus methods to develop a HNA tool. Using a randomized stratified systematic sampling method adjusted for sex, age, and districts, 57 registered persons (27 severe and 30 mild cases) with brain disorders dwelling in Seoul, South Korea were chosen and medical specialists investigated all of the subjects with the developed tools.

**Results:** The HNA tool for brain disorders we developed included four categories: 1) medical interventions and operations, 2) assistive devices, 3) rehabilitation therapy, and 4) regular follow-up. This study also found that 71.9% of the subjects did not receive appropriate medical care, which implies that the severity of their disability is likely to be exacerbated and permanent, and the loss irrecoverable.

**Conclusions:** Our results showed that the HNA tool for persons with brain disorders based on unmet needs defined by physicians can be a useful method for evaluating the appropriateness and necessity of medical services offered to the disabled, and it can serve as the norm for providing health care services for disabled persons. Further studies should be undertaken to increase validity and reliability of the tool. Fundamental research investigating the factors generating or affecting the unmet needs is necessary; its results could serve as basis for developing policies to eliminate or alleviate these factors.

**Key words:** Disabled persons, Brain disorders, Needs assessment, Unmet needs

### INTRODUCTION

Persons with disabilities are less likely to utilize health care services [1-4]. The disabled can also have several special health

care needs that differ from those of non-disabled persons [5]; the disabled are more likely to be vulnerable to physical conditions that require medical treatment, less likely to have opportunities for health promotion and medical services for prevention, more likely to experience the early onset of chronic diseases, and more likely to have secondary dysfunction due to disease morbidity. Therefore, more comprehensive and continuous health care services are needed for the disabled because they have special health needs related to their disabilities [1,6,7]. Nevertheless, many studies have indicated that there are significant unmet needs in health care utilization among the disabled, not only in Korea, but also in other countries [8-12]. Wright et al. [13] defined 'unmet needs' as the dif-

**Received:** May 26, 2013; **Accepted:** September 6, 2013

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ference between current medical utilization and needs, and suggested the development of health needs assessment (HNA) tools to measure such unmet needs. However, the process of developing HNA tool for the disabled in Korea is very difficult because little is known about the detailed content and scope of unmet needs among persons with disabilities. For example, according to the Survey on Disabled Persons in 2000 conducted by the Korea Institute for Health and Social Affairs, persons with disabilities in Korea wanted foremost income security and expanded health care coverage from the government and community in general [8]. However, this survey did not describe in detail the contents of the medical services required by disabled persons. An interview of persons with disability and medical experts revealed that both groups believed appropriate medical services are not being provided to the disabled in Korea. However, disabled persons could not clearly identify the specific medical services they needed nor could medical experts articulate an explanation of which medical services the patients require, as consensus could not be reached among the medical experts [6]. That is, in the current situation, not only medical experts but also the disabled themselves cannot clearly define what services the disabled need and to what extent unmet needs exist. Therefore, developing an HNA tool for the disabled is very important; it is the first step toward grasping the extent of the unmet needs of the disabled. Among disabilities in South Korea, brain disorders include neurological and neurosurgical disorders such as cerebral palsy, stroke, traumatic brain injury, excluding psychiatric or mental disorders; brain disorders are considered to be the most serious type of disability, and the extent of the unmet needs of those with brain disorders is significant in Korea [14].

This study aimed to develop a HNA tool for persons with brain disorders, and to apply the tool to assess the unmet needs of persons with brain disorders dwelling in Seoul, Korea.

## METHODS

To develop a HNA tool for disabled persons with brain disorders, we created a consensus panel composed of specialists with medical practice experience of over 10 years in physical medicine and rehabilitation. The panel consisted of six members, identified from the recommendation of previous studies on developing clinical practice guidelines [15-17]. The six specialists included three medical doctors from the National Rehabilitation Center in Korea, two more specialists that they

recommended, and one specialist recommended by the Korea Differently Abled Federation, a federation of 28 disabled persons' organizations. One specialist prepared a draft of the HNA tool to be distributed among panel members via email and then revised it after gathering their comments. Panel-wide meetings followed for further development of the revision. During this process, general consensus on the principles of HNA tool development and criteria for evaluation of the HNA tool were obtained. First of all, in this study, "health needs" was operationally defined as the need for medical services that can be provided by doctors and hospitals. Second, it was decided that the HNA tool should be developed for community-dwelling disabled persons with brain disorders after disability registration, in order to assess the adequacy of medical service provision for them. Third, only disabled persons aged 20 or over were included, because those aged younger than 20 have too many complex factors that are barriers for standardizing the disability in the HNA tool. Fourth, an ultimate goal of required medical services for disabled persons was set up. For disabled persons with brain disorders, their functional damage should be limited to the greatest possible extent, and they should be able to maintain or return to everyday life activities as much as possible. Finally, the four evaluation criteria of the HNA tool included assessment of the necessity and appropriateness of regular follow-up, medical interventions and operations, usage of medical assistive devices, and rehabilitation therapy. After gathering consensus on the general principles and evaluation criteria of the HNA tool already explained above, the panel group developed specific decision criteria for service needs and appropriateness for disabled persons with brain disorders.

The subjects in this study consisted of disabled persons with brain disorders dwelling in the Seoul area. We linked the Ministry of Health and Welfare's registration data (as of the end of 2004) of the disabled and the National Health Insurance Corporation's qualification data by using encrypted resident registration numbers. Then we carried out randomized stratified systematic sampling based on the severity of disability taking into account sex, age group, and area of residence (gu) for persons with brain disorders examined in this study. By depending on the person's severity of disability (severe, levels 1-3; mild, levels 4-6), 30 persons in each group, summing to a total of 60 persons, were extracted as a sample, using randomized stratified systematic sampling by sex, age, and area of residence (gu). To prepare for the case in which some of the selected disabled persons refuse medical treatment, we sampled another

2400 candidates as an alternate pool with the same disability type, severity of disability, sex, age group, and area of residence. The final sample included 57 persons (27 severe and 30 mild cases) with brain disorders who each agreed to participate in the survey (Table 1).

The HNA tool developed in this study was used by medical specialists to assess the unmet needs of disabled persons with brain disorders. The participants were transported to health care institutions. For those who were immobile and unable to pay a visit to the hospital, medical staff conducted home visits. In order to test the reliability of the HNA tool, two medical doctors independently evaluated 10 disabled persons with brain disorders. The detailed evaluation criteria were the following: 'appropriate' (AP), 'inappropriate' (IP), and 'not applicable' (NA). The medical doctor evaluating the patient would choose 'AP' when concluding that a patient needed to receive certain medical services (i.e., medical interventions or operations) and the patient had actually received the appropriate services; 'IP' when a patient needed to receive a certain medical service but the patient did not receive appropriate services; and 'NA' when a patient did not need to receive a certain medical service regardless of whether the patient received the service or not. The results were then compared with a kappa index using SPSS version 12.0 for Korea (SPSS Inc., Chicago, IL, USA).

## RESULTS

The consensus panel developed the HNA tool for persons with brain disorders. Table 2 shows the detailed evaluation criteria, which comprised four evaluation categories: 1) medical interventions and operations, 2) assistive devices, 3) rehabilitation therapy, and 4) regular follow-up. In step 1, each rehabilitation therapy specialist first checked the patient's status, medically examined the persons with brain disorders by interview, and then physically examined the patients. Second, the specialist determined whether a treatment is needed for casual diseases of the disability and sequelae. Third, the specialist examined whether treatment was necessary for preservation and improvement of function according to of the need for assistive devices and prosthetic rehabilitation, in cases where the severity of disability was lessened and secondary prevention was effective. In step 2, the specialist asked which treatments the patient had been receiving, and then evaluated the appropriateness of the treatments, with reference to the prior

evaluation results from step 1 (the need for treatment). This appropriateness evaluation also was applied to the other categories: assistive devices and rehabilitation therapy. After the evaluation of both step 1 for the needs and step 2 for the appropriateness of medical service provision, in step 3 the specialist checked whether the patient needed follow-up care intensively or regularly. Finally, the specialist decided whether the patient had been appropriately or inappropriately managed in general (Table 2).

For the disabled persons with brain disorders, 91.2% required medical intervention or an operation (Table 3). Among them, 40.4% had received appropriate treatment. 66.7% of the subjects required an assistive device, but 26.3% of them were actually using an appropriate assistive device. Rehabilitation therapy was needed by 64.9% of the subjects, but only 10.8% were receiving appropriate care. As for regular follow-up, 96.5% required it, and 50.9% had at least one follow-up treatment each year, which was the highest rate in all categories. In sum, only 28.1% of subjects with brain disorders had been receiving appropriate medical care. That is, 71.9% of the subjects had an unmet need of some kind related to the utilization of medical services.

We calculated the index of coincidence between the two rehabilitation therapy specialists to test the reliability of the HNA tool for disabled persons with brain disorders. Scores were given on each evaluation criterion for their appropriateness by the two doctors for the 10 subjects, and then the results were compared. The scores were categorized as 'AP', 'IP', and 'NA'. The scorers understood the evaluation criteria first, and gave scores independently, not by consensus on each category. The results presented a high simple agreement ranging between 0.6 and 1.0 except for rehabilitation therapy, while the kappa index also showed a perfect simple agreement of 1.0 ( $p < 0.01$ ) for assistive devices, regular follow-up, and final appropriateness, ranging from 0.531 to 0.737 ( $p < 0.05$ ) (Table 4).

## DISCUSSION

Our core study question was whether appropriate and essential health care services were being provided to the disabled. Even though measuring the special needs of persons with disabilities is very important, there is no research that has used an HNA tool for the disabled [18]. Therefore, we developed an HNA tool for persons with brain disorders based on professionally defined needs and conducted a pilot test using

**Table 1.** General characteristics of each participant with a brain disorder

| ID | Sex    | Age | Grade | Severity | Year of occurrence | Year of registration | Cause of disability           |
|----|--------|-----|-------|----------|--------------------|----------------------|-------------------------------|
| 1  | Male   | 67  | 5     | Mild     | 2002               | 2004                 | Stroke                        |
| 2  | Male   | 62  | 5     | Mild     | 1980               | 2004                 | Traumatic brain injury        |
| 3  | Male   | 57  | 5     | Mild     | 2002               | 2004                 | Traumatic cerebral hemorrhage |
| 4  | Male   | 71  | 5     | Mild     | 1997               | 2003                 | Parkinson's disease           |
| 5  | Female | 62  | 5     | Mild     | 2003               | 2003                 | Cerebral tumor                |
| 6  | Male   | 63  | 4     | Mild     | 2000               | 2002                 | Stroke                        |
| 7  | Male   | 53  | 4     | Mild     | 2004               | 2004                 | Cerebral infarction           |
| 8  | Male   | 77  | 5     | Mild     | 1999               | 2002                 | Stroke                        |
| 9  | Male   | 61  | 4     | Mild     | 1999               | 2001                 | Stroke                        |
| 10 | Male   | 56  | 2     | Severe   | 2002               | 2003                 | Spinal cord injury            |
| 11 | Male   | 63  | 3     | Severe   | 2002               | 2004                 | Stroke                        |
| 12 | Female | 69  | 3     | Severe   | 2003               | 2004                 | Cerebral hemorrhage           |
| 13 | Male   | 67  | 5     | Mild     | 2002               | 2003                 | Cerebral infarction           |
| 14 | Male   | 45  | 5     | Mild     | 2000               | 2002                 | Cerebral hemorrhage           |
| 15 | Female | 68  | 1     | Severe   | 2003               | 2003                 | Cerebral hemorrhage           |
| 16 | Female | 63  | 1     | Severe   | 1992               | 2000                 | Cerebral hemorrhage           |
| 17 | Female | 71  | 3     | Severe   | 1998               | 2001                 | Stroke                        |
| 18 | Male   | 67  | 2     | Severe   | 1998               | 2001                 | Cerebral hemorrhage           |
| 19 | Male   | 65  | 2     | Severe   | 1998               | 2001                 | Parkinson's disease           |
| 20 | Male   | 65  | 2     | Severe   | 1991               | 2001                 | Cerebral infarction           |
| 21 | Male   | 37  | 4     | Mild     | 2000               | 2001                 | Traumatic brain injury        |
| 22 | Male   | 66  | 4     | Mild     | 1993               | 2000                 | Cerebral infarction           |
| 23 | Male   | 45  | 4     | Mild     | 2000               | 2004                 | Stroke                        |
| 24 | Male   | 66  | 6     | Mild     | 1999               | 2000                 | Cerebral infarction           |
| 25 | Female | 54  | 2     | Severe   | 1998               | 2001                 | Cerebral infarction           |
| 26 | Male   | 47  | 2     | Severe   | 2002               | 2002                 | Stroke                        |
| 27 | Male   | 52  | 4     | Mild     | 2002               | 2002                 | Cerebral infarction           |
| 28 | Male   | 59  | 3     | Severe   | 2000               | 2002                 | Cerebral hemorrhage           |
| 29 | Male   | 61  | 5     | Mild     | 1998               | 2002                 | Stroke                        |
| 30 | Male   | 48  | 2     | Severe   | 2002               | 2003                 | Cerebral hemorrhage           |
| 31 | Male   | 68  | 4     | Mild     | 1996               | 2001                 | Cerebral hemorrhage           |
| 32 | Male   | 62  | 4     | Mild     | 2001               | 2002                 | Stroke                        |
| 33 | Male   | 64  | 2     | Severe   | 2001               | 2002                 | Stroke                        |
| 34 | Male   | 67  | 3     | Severe   | 2004               | 2004                 | Cerebral hemorrhage           |
| 35 | Female | 58  | 3     | Severe   | Unknown            | 2003                 | Cerebral palsy                |
| 36 | Male   | 62  | 4     | Mild     | 1972               | 2000                 | Traumatic cerebral hemorrhage |
| 37 | Male   | 47  | 5     | Mild     | 1994               | 2001                 | Stroke                        |
| 38 | Male   | 56  | 4     | Mild     | 1992               | 2002                 | Cerebral infarction           |
| 39 | Male   | 70  | 4     | Mild     | 2001               | 2002                 | Cerebral hemorrhage           |
| 40 | Male   | 50  | 4     | Mild     | 2003               | 2003                 | Cerebral hemorrhage           |
| 41 | Male   | 71  | 4     | Mild     | 2000               | 2000                 | Stroke                        |
| 42 | Female | 63  | 4     | Mild     | 1999               | 2000                 | Cerebral infarction           |
| 43 | Male   | 34  | 6     | Mild     | Unknown            | 2003                 | Essential tremor              |
| 44 | Male   | 49  | 6     | Mild     | 2001               | 2002                 | Stroke                        |
| 45 | Male   | 23  | 2     | Severe   | 1999               | 2000                 | Cerebral tumor                |
| 46 | Male   | 64  | 6     | Mild     | 2000               | 2003                 | Unknown                       |
| 47 | Male   | 63  | 6     | Mild     | 1985               | 2003                 | Cerebral hemorrhage           |
| 48 | Male   | 69  | 3     | Severe   | 1985               | 2000                 | Parkinson's disease           |
| 49 | Female | 68  | 1     | Severe   | 2000               | 2001                 | Cerebral infarction           |
| 50 | Male   | 57  | 1     | Severe   | 2000               | 2002                 | Cerebral infarction           |
| 51 | Female | 42  | 1     | Severe   | 2000               | 2001                 | Cerebral hemorrhage           |
| 52 | Male   | 35  | 1     | Severe   | 2000               | 2003                 | Cerebral hemorrhage           |
| 53 | Male   | 68  | 3     | Severe   | 2001               | 2004                 | Cerebral infarction           |
| 54 | Male   | 68  | 2     | Severe   | 1997               | 2003                 | Cerebral infarction           |
| 55 | Male   | 64  | 2     | Severe   | 1981               | 2003                 | Cerebral hemorrhage           |
| 56 | Male   | 63  | 1     | Severe   | 1996               | 1997                 | Cerebral hemorrhage           |
| 57 | Male   | 83  | 1     | Severe   | 1990               | 2000                 | Stroke                        |

**Table 2.** The health needs assessment tool for persons with brain disorders: evaluation criteria

|        | Treatment for causal diseases and sequelae   | Treatment for functional preservation and improvement  |   |
|--------|--|--|---|
|        | Medical intervention and operation (A)   | Assistive devices (B)  |   |
|        |  | Rehabilitation therapy (C)   |   |
| Step 1 | <p><b>Necessity<sup>1</sup></b></p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p>A1. Is treatment for the secondary prevention (of high blood pressure, hyperlipidemia, stroke, and cardiovascular disease) necessary?</p> <p>A2. Does the patient complain of pain limiting activities of daily living?</p> <p>A3. Does the patient have muscle contraction limiting activities of daily living?</p> <p>A4. Does the patient currently have a pressure ulcer or has one developed in the last three months?</p> <p>A5. Does the patient need regular bowel movement management and have difficulty expressing and handling the need for defecation independently? (e.g., laxative prescription needed)</p> <p>A6. Does the patient need management of urination and have difficulty expressing and handling the need for urination independently?</p> <p>A7. Does the patient have severe spasticity limiting activities of daily living?</p> <p>A8. Has the patient undergone bronchotomy (respiratory care)?</p> | <p>B1. Cases where muscle strength of the ankle is less than 50%, toe clearance is not possible during ambulation, or moving left and right is not possible (ankle-foot orthosis)</p> <p>B2. Cases where there is contracture of the hand (wrist and hand orthosis)</p> <p>B3. Cases where muscle strength of the shoulder is less than 50% and subluxation of the cartilage (arm sling)</p> <p>B4. Cases where there is a lack of stability in ambulation (walking aids: crutch, cane, walker, etc.)</p> <p>B5. Cases where walking cannot be performed independently (manual wheelchair with or without reclining back)</p> <p>B6. Cases where cognitive abilities are proficient enough to operate a mobile vehicle as well as to maintain one handed function, and movement of long distance is needed (power wheelchair or scooter)</p> | <p>C1. Cases where there is a progression of joint contracture or paralysis (range of motion and muscle strengthening exercise)</p> <p>C2. Cases where ambulation cannot be performed independently (ambulation exercise)</p> <p>C3. Cases where there is paralysis and contracture of the upper extremity (functional training of the upper extremities - occupational therapy)</p> <p>C4. Cases where activities of daily living are dependent on others (activities of daily living exercise)</p> <p>C5. Cases where communication through language is not fluent (speech therapy)</p> <p>C6. Cases where there is a limitation in activities of daily living due to cognitive and perceptual disabilities (cognitive therapy)</p> <p>C7. Cases where a normal diet is inadequate due to dysphagia (dysphagia management)</p>  |
| Step 2 | <p><b>Appropriateness<sup>2</sup></b></p> <p><input type="checkbox"/> AP</p> <p><input type="checkbox"/> IP</p> <p><input type="checkbox"/> NA</p> <p>1. Medication and medical treatment regarding A1 is received on a regular basis by a physician specialist</p> <p>2. A treatment of medications, injections, or physical therapy regarding A2 is being received at a medical facility</p> <p>3. A treatment of physical therapy, orthosis, or surgery regarding A3 is being received at a medical facility</p> <p>4. Professional medical treatment regarding A4 has been received</p> <p>5. The problems stated in A5 have been medically treated and are cared for by caregivers</p> <p>6. Regular urination and cleanliness (A6) is sustained by caregivers</p> <p>7. Medication, ROM exercise, or injection treatment regarding A7 is received through a physician's prescription</p> <p>8. Cleanliness and regular replacement regarding A8 is being maintained</p>  | <p>1. Ankle-foot orthosis is prescribed by a medical facility in cases of B1</p> <p>2. Wrist and hand orthosis is prescribed by a medical facility in cases of B2</p> <p>3. The arm is being sustained by an arm sling in cases of B3</p> <p>4. Walking aids prescribed by a physician are used in cases of B4</p> <p>5. A wheelchair is retained in cases of B5</p> <p>6. The power wheelchair or scooter is retained by the physician's diagnosis and prescription in cases of B6</p>  | <p>1. Regular treatment is received, or contracture is prevented by an assistive device in cases of C1</p> <p>2. The patient's improvement in ambulation is expected by treatment in cases of C2</p> <p>3. Treatment is currently received or progression is prevented by an assistive device in cases of C3</p> <p>4. The patient receives treatment when improvement of the independence level in activities of daily living is expected, and he/she sustains the activities with a caregiver's assistance in cases of C4</p> <p>5. The patient is currently receiving treatment or learning new ways of communication through education in cases of C5</p> <p>6. The patient receives treatment when improvement in cognitive function is expected in cases of C6</p> <p>7. Dysphagia examination is received from a medical facility, and dietary modification or swallowing therapy is provided in cases of C7</p> |
| Step 3 | <p><b>Intensive management</b></p> <p>A regular check-up is needed at least once every 1-2 months</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><b>Appropriateness<sup>3</sup></b></p> <p><input type="checkbox"/> AP</p> <p><input type="checkbox"/> IP</p> <p><input type="checkbox"/> NA</p> <p>Final Appropriateness</p> <p><input type="checkbox"/> AP</p>  | <p><b>Regular follow-up</b></p> <p>A regular check-up is needed at least once or twice every year</p>  | <p><b>Regular management</b></p> <p>A regular check-up is needed at least once or twice every year</p>  |
| Step 4 | <p><input type="checkbox"/> AP</p>   | <p><input type="checkbox"/> IP</p>   |   |

AP, appropriate; IP, inappropriate; NA, non-applicable.

<sup>1</sup>Doctors checked whether it was necessary or not, as well as whether a patient had received it or not.

<sup>2</sup>Doctors checked one of three response options, AP, IP, or NA, as compared to their prior evaluation results from step 1.

<sup>3</sup>Doctors checked one of three response options, AP, IP, or NA, as compared to their prior evaluation results from step 1 and 2.

**Table 3.** Unmet needs of persons with brain disorders

| Category                           | AP (A) | IP (B) | NA (C) | Total <sup>1</sup> (D) | Need <sup>2</sup> (E) | AR <sup>3</sup> (F) | Unmet need <sup>4</sup> (G) |
|------------------------------------|--------|--------|--------|------------------------|-----------------------|---------------------|-----------------------------|
| Medical intervention and operation | 21     | 31     | 5      | 57                     | 91.2%                 | 40.4%               | 59.6%                       |
| Assistive device                   | 10     | 28     | 19     | 57                     | 66.7%                 | 26.3%               | 73.7%                       |
| Rehabilitation therapy             | 4      | 33     | 20     | 57                     | 64.9%                 | 10.8%               | 89.2%                       |
| Regular follow-up                  | 28     | 27     | 2      | 57                     | 96.5%                 | 50.9%               | 49.1%                       |
| Final appropriateness              | 16     | 41     | 0      | 57                     | 100.0%                | 28.1%               | 71.9%                       |

AP, appropriate; IP, inappropriate; NA, non-applicable; AR, appropriate rate.

<sup>1</sup>Total (D)=A+B+C+D.

<sup>2</sup>Need (E)=(A+B)/D × 100.

<sup>3</sup>AR (F)=A/(A+B) × 100.

<sup>4</sup>Unmet need (G)=1-F.

**Table 4.** Inter-scorer reliability of the health needs assessment tool for persons with brain disorders

| Category                           | Simple agreement | Kappa index | Standard error | p-value |
|------------------------------------|------------------|-------------|----------------|---------|
| Medical intervention and operation | 0.900            | NA          | -              | -       |
| Assistive device                   | 1.000            | 1.000       | 0.000          | <0.001  |
| Rehabilitation therapy             | 0.600            | NA          | -              | -       |
| Regular follow-up                  | 1.000            | 1.000       | 0.000          | 0.002   |
| Final appropriateness              | 1.000            | 1.000       | 0.000          | 0.002   |

NA, non-applicable.

the tool in assessing the appropriateness of medical services provided to the disabled dwelling in the Seoul area. The results showed that the HNA tool can play important roles: It can specify the essential medical services needed for the disabled and can evaluate whether such services are being properly offered, and it can serve as the norm for providing health care services for disabled persons. That is, by having these tools as the norm for medical services for the disabled and evaluating persons with a disability using such criteria, it can provide us with information on the extent of unmet needs what areas are especially weak. This study also showed the possibility that development of HNA tools for the disabled with not only brain disorders but also other types of disability can be useful for evaluating whether they received appropriate medical interventions and operations, assistive devices, and rehabilitation therapy according to their individual medical needs.

However, during the process of developing the HNA tool, we had to establish several critical principles. First, we clearly defined the terms regarding needs. The definitions of Wright et al. [13] was adopted: 'want' is the need as felt by an individual, which is a 'demand' when it is expressed; 'need' is defined by a norm, and 'unmet needs' are the discrepancy between the current medical utilization and needs. According to this criterion, most research regarding unmet needs could be classified as studies about dealing with the demands of patients

[8-12]. Therefore, there is a lack of reference studies based on an HNA tool for the disabled. Second, we asked ourselves who should determine the needs of persons with brain disorders. That is, whose perspective should be reflected by the tool? This was very important question because the need for health care can be determined by not only medical experts but also patients, purchasers, and government agencies [13]. Recently, the importance of assessing needs from the perspectives of actual patients and the public rather than those of medical professionals has been emphasized [19]. However, we decided to develop the HNA tool based on professionally defined need assessment for several reasons. First of all, taking the perspective of expert who is familiar with many different patient cases is more objective than that of patients, who tend to take a subjective stance with greater concern for what is critical for their own health [20]. In addition, given that no supporting materials on medical services needed by disabled persons are available, developing the first HNA tool for the disabled based on the needs identified by medical professionals would be an excellent starting point, and then incorporating the input of other stakeholders in a later version would be appropriate.

This study of four categories of unmet needs found significant levels of unmet needs. Kersten et al. [12] suggested that persons with a disability and associated additional health care needs should be provided with medical services consisting of

social services, physical therapy, assistive devices, and day care center services. However, our results showed that 71.9% of subjects were not likely to receive adequate medical services for their disability after registering their disability status. In addition, only 40.4% of disabled persons with brain disorders received appropriate medical interventions and operations. Therefore, the health status of the remaining 59.6% could be very likely to deteriorate. With regard to assistive devices, the rate of appropriateness was only 26.3%. When persons with brain disorders do not have appropriate assistive devices, the possibility of improvement in their functional status is reduced, so they should be provided with appropriate devices. The appropriateness of rehabilitation therapy for disabled persons with brain disorders was only 10.8%, despite the importance of this care. This finding showed that disabled persons with brain disorders experienced discontinuity in rehabilitation therapy as well as inadequate provision of treatment. This could increase the likelihood of a disability becoming permanent. Although regular follow-up is critical during the window of opportunity for doctors to formulate a plan for treatment, rehabilitation, and the prevention of progression of the disability, 49.1% could not access regular follow-up at least once a year. This finding implies that disabled persons with brain disorders are often excluded from local communities and lack knowledge of the medical services they require, even when their disability grade has been changed at the time of registration of the disability. Therefore, their health status can be very likely to be exacerbated and permanent, and the loss irrecoverable, when appropriate medical treatments in the four categories have not been appropriately provided. Additionally, this study showed that persons with a disability could not access regular follow-up (at least once a year) in spite of the importance of the regular follow-up. This finding implies that they are vulnerable and neglected to access medical services, especially for preventing the progression of the disability. Thus, the HNA tool can be used as a baseline for developing regular checkup guidelines for the disabled with brain disorders, and it makes possible tracking their medical histories annually (or at another regular interval) for understanding their needs for earlier medical intervention as well as social services to support their medical treatments.

However, the research methodologies adopted in this study have several limitations. First, we used the consensus method for developing the assessment tool. This method can be effectively used in developing an assessment tool when there ex-

ists great uncertainty in medical technologies or policies for clinical medicine or health care, but it may include a selection bias when choosing experts for the consensus panel group, who may not represent the common views of all professionals in the field. In addition, it is difficult to evaluate to what extent agreement has been reached, and other studies in different settings and on other topics may have different consensus processes and levels of agreement than the present study [21-24]. Nevertheless, considering the absence of existing research related to an HNA tool for the disabled on what medical services should be provided clinically and politically, this study is meaningful as a trial of a newly developed tool for persons with a disability, in that it achieved the highest possible level of agreement among panel members by means of individual interviews, email exchanges of comments, and panel-wide meetings until a consensus was reached on the tool's evaluation criteria. The second limitation concerns the validity and reliability of the needs assessment tool. To validate the needs assessment tool, this study considered content validity, which allows for the appropriateness of objectives established by experts [25]. Other studies have also used content validity in their tool development process, but tested the validity of the tools using convergent validity between the disability grades of the Ministry of Health and Welfare and scores on the Korean Activities of Daily Living (K-ADL) tool [26,27]. However, this study could not adopt such procedures for testing the validity of our newly developed tool because there was no standard available with which to compare the HNA tool. Thus, it was not feasible to apply validity tests using criterion validity, convergent validity, or discriminant validity. Consequently, content validity was the only option for validating the tool. However, given that this study was the first attempt at developing such a tool for the disabled, content validity using a consensus panel at the academy-wide level was the most appropriate way to maximize the validity of this study. In terms of reliability of the assessment tool, this study used nominal variables (appropriate, inappropriate, and not applicable) on each evaluation criterion answered by two scorers to test reliability, so that Cohen's kappa index (rather than Cronbach's  $\alpha$  index) seemed the more appropriate measure. However, a relatively lower agreement level was observed in some cases of rehabilitation therapy, and such findings suggested that further clarification of the evaluation standards for rehabilitation therapy and a larger sampling pool in future studies are required. Third, this study was conducted with a randomized stratified systematic sam-

pling method of disabled persons residing in the Seoul area, according to sex, age, area of residence (gu) by the disability type and severity of the disability. However, in many cases, the disabled persons refused medical treatment, so that this study should have extracted the sample with multiples of 40 to obtain the sample we had planned. Therefore, this study might have a sampling risk in representing the disabled living in Seoul as well as generalizing them nationwide.

In spite of several limitations in its methodology, this study was significant in that it was the first to develop and apply an HNA tool for persons with a brain disorder based on unmet needs defined by physicians. This tool can make possible the evaluation of the appropriateness and necessity of medical services offered to the disabled. However, further studies should be undertaken to increase the validity and reliability of the tool. In addition, a nationwide survey with a larger sample size to allow for generalization across the country should be conducted. Lastly, in this study, we only focused on the extent of unmet needs among persons with brain disorders. Therefore, in the near future, fundamental research investigating the factors generating or affecting unmet needs is needed; this can serve as the basis for developing policies for eliminating or alleviating these factors.

## ACKNOWLEDGEMENTS

This study was performed with financial support from the National Health Insurance Corporation in Korea.

## CONFLICT OF INTEREST

The authors have no conflicts of interest with the material presented in this paper.

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