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

Yoon Kim^{1,2}, Sang June Eun³, Wan Ho Kim⁴, Bum-Suk Lee⁴, Ja-Ho Leigh⁴, Jung-Eun Kim⁵, Jin Yong Lee⁶

¹Department of Health Policy and Management, Seoul National University College of Medicine, Seoul; ²Institute of Health Policy and Management, Seoul National University Medical Research Center, Seoul; ³Regional Cardiocerebrovascular Center, Seoul National University Bundang Hospital, Seongnam; ⁴Department of Rehabilitation Medicine, National Rehabilitation Center, Seoul; ⁵Center for Social Sciences, Seoul National University, Seoul; ⁶Public Health Medical Service, SMG-SNU Boramae Medical Center, Seoul, Korea

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

Received: May 26, 2013; Accepted: September 6, 2013 Corresponding author: Jin Yong Lee, MD, PhD 20 Boramae-ro 5-gil, Dongjak-gu, Seoul 156-707, Korea Tel: +82-2-870-2165, Fax: +82-2-831-0174 E-mail: jylee2000@gmail.com 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-

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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

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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 followup, 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

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

| 1Meia67.5Mid902.903.< | ID | Sex | Age | Grade | Severity | Year of occurrence | Year of registration | Cause of disability |
|--|----|--------|----------|-------|----------|-----------------------|-------------------------|-------------------------------|
| 2 Male 52 Mid 1980 2044 Traunaic cerchal homorhage 4 Male 71 5 Mid 1907 2033 Particatic cerchal homorhage 6 Male 53 4 Mid 2010 2023 State 6 Male 53 4 Mid 2010 2024 State 7 Male 53 4 Mid 1984 2010 State 8 Male 77 5 Mid 1984 2010 State 11 Male 77 5 Mid 1984 2010 State 12 Fondal 88 3 Store 2030 2034 State 13 Male 77 5 Mid 2030 2034 Contral homorhage 14 Male 76 5 Mid 2030 2034 Contral homorhage 13 Male 77 5 Mid 2030 2034 Contral homorhage 14 Male 71 State 2031 2034 Contral homorhage 15 Fondal 72 State 2034 2034 Contral homorhage <tr< td=""><td>1</td><td>Male</td><td>67</td><td>5</td><td>Mild</td><td>2002</td><td>2004</td><td>Stroke</td></tr<> | 1 | Male | 67 | 5 | Mild | 2002 | 2004 | Stroke |
| 3Maie975Mid1922014Tubinori coertal herrorroge5Fenale025Mid203203Conterpl harror5Maia034Mid204204Sirake7Maia034Mid204204Sirake9Maia75Mid1984201Sirake9Maia62Sirake202204Sirake10Maia65Mid202204Control information11Maia65Mid202203Control information13Maia65Mid202203Control information14Maia65Mid202203Control information15Fenale65Mid202203Control information16Fenale61Sirate203Control information17Fenale61Sirate203Control information18Fenale64Mid203Control information19Fenale64Mid203Control information19Maia66Mid198201Fenale19Maia66Mid198201Control information19Maia66Mid198201Gontrol information19M | 2 | Male | 62 | 5 | Mild | 1980 | 2004 | Traumatic brain injury |
| 4 Maie 71 5 Mid 197 20.0 Pertainion's disesse 5 Franka 62 5 Mid 2000 2022 Stroke 6 Mala 53 4 Mid 198 2022 Stroke 9 Mala 7 5 Mid 198 2022 Stroke 10 Mala 61 4 Mid 198 2022 Stroke 11 Mala 61 3 Stroke 2022 2001 Stroke 12 Franke 63 3 Storee 2032 Candral Informating 13 Mala 64 5 Mid 2002 2031 Candral Informating 14 Mala 63 1 Storee 1932 2031 Candral Informating 15 Franke 63 1 Storee 1932 2011 Candral Informating 17 Franke 63 1 Storee 1932 2011 Candral Informating 18 Mala 65 2 Storee 1932 2011 Candral Informating 19 Mala 7 4 Mid 2002 201 | 3 | Male | 57 | 5 | Mild | 2002 | 2004 | Traumatic cerebral hemorrhage |
| 5Fendle625Mile20032003Concept lumm7Male634Mile10042004Stoke7Male175Mile19942014Stoke9Male175Mile19942014Stoke9Male632Stoke20222014Stoke11Male662Stoke20222014Stoke12Fendle63Stoke20222014Stoke13Male675Mile20202020Cardeni heroringe14Male675Mile20202020Cardeni heroringe15Fendle631Stoke19922000Cardeni heroringe16Fendle631Stoke19922000Cardeni heroringe17Fendle631Stoke19922000Cardeni heroringe18Male672Stoke19982010Parkinge19Male672Stoke19982010Parkinge20Male674Mile19982010Parkinge21Male638Mile19982010Parkinge22Male64Mile19982010Cardeni heroringe23Male64Mile19982010Stoke24Male64 <td>4</td> <td>Male</td> <td>71</td> <td>5</td> <td>Mild</td> <td>1997</td> <td>2003</td> <td>Parkinson's disease</td> | 4 | Male | 71 | 5 | Mild | 1997 | 2003 | Parkinson's disease |
| 6 Male 63 4 Mild 2000 2012 Synke 8 Male 73 5 Mild 198 2010 Strake 9 Male 64 Mild 198 2010 Strake 10 Male 63 2 Store 2012 2031 Store 11 Male 63 3 Store 2012 2014 Store 12 Fenale 69 3 Store 2003 2014 Dechol Interritory 13 Male 67 5 Mild 2007 2013 Dechol Interritory 14 Male 63 1 Store 2013 Dechol Interritory 15 Fenale 63 1 Store 198 2014 Dechol Interritory 17 Fenale 71 3 Store 198 2014 Dechol Interritory 18 Male 65 2 Store 198 2014 Dechol Interritory 21 Male 65 2 Store 198 2014 Dechol Interritory 22 Male 65 2 Store 198 2014 Dechol In | 5 | Female | 62 | 5 | Mild | 2003 | 2003 | Cerebral tumor |
| 7 Maia 77 5 Mide 904 Onche infraction 9 Maia 77 5 Mide 98 201 Shoke 9 Maia 74 5 Mide 98 201 Shoke 9 Maia 56 2 Soren 202 203 Sonke 11 Maia 67 5 Mid 202 203 Canden Immutage 12 Finale 68 1 Soren 202 203 Canden Immutage 14 Maia 45 5 Mid 200 Canden Immutage 16 Finale 68 1 Soren 192 200 Canden Immutage 16 Finale 68 1 Soren 192 200 Canden Immutage 17 Finale 68 1 Soren 192 200 Canden Immutage 18 Maia 67 2 Soren 198 201 Canden Immutage 20 Maia 68 4 Mid 198 201 Canden Immutage 21 Maia 68 1 Mid 198 201 Canden Immutage | 6 | Male | 63 | 4 | Mild | 2000 | 2002 | Stroke |
| BNulaNoSMild19992022Stoka10Nula514Mild19992014Stoka11Nale532Severe20032004Spiral cordinjoy12Fensle633Severe20032004Spiral cordinjoy13Nale57Mild20022003Caebch humorhage14Nale455Mild2002Caebch humorhage15Fanalo631Sovica19822001Caebch humorhage16Fanalo631Sovica19842011Stoka17Fanalo632Sovica19842011Stoka18Mala652Sovica19842011Caebcha humorhage19Mala652Sovica19842011Caebcha humorhage20Mala652Sovica19842011Caebcha humorhage21Mala654Mild19932010Caebcha humorhage22Mala654Mild19892011Caebcha humorhage23Mala654Mild19892011Caebcha humorhage24Mala654Mild19892011Caebcha humorhage25Fanalo5Mild19892011Caebcha humorhage26Mala64Sovica2022Stoka< | 7 | Male | 53 | 4 | Mild | 2004 | 2004 | Cerebral infarction |
| 9Male614Male910Stoke2011Stoke11Male632Severe20022034Stoke12Fanale633Severe20032034Cardeal infraction13Male675Male20032034Cardeal infraction14Male631Severe19222034Cardeal infraction16Fanale631Severe19822034Cardeal infraction16Fanale713Severe19842010Cardeal infraction17Fanale632Severe19842011Cardeal infraction18Male652Severe19842011Cardeal infraction20Male664Male19832010Cardeal infraction21Male664Male20042044Stoke22Male664Male20042044Stoke23Male677Severe19842010Cardeal infraction24Male684Male2002Cardeal infraction25Fanale7Severe19842014Stoke26Male7Severe19842014Cardeal infraction27Male684Male2022Cardeal infraction28Male7Severe1984 <td< td=""><td>8</td><td>Male</td><td>77</td><td>5</td><td>Mild</td><td>1999</td><td>2002</td><td>Stroke</td></td<> | 8 | Male | 77 | 5 | Mild | 1999 | 2002 | Stroke |
| 10Male562Severe20022004Styne12Forolo633Severe20042014Caraba informinge12Forolo675Mid20032024Caraba informinge13Male675Mid2003Caraba informinge14Male681Severe20132013Caraba informinge15Famale681Severe19822010Caraba informinge16Famale631Severe19812011Caraba informinge17Fanale672Severe19882011Caraba informinge18Male672Severe19812011Caraba informinge19Male662Severe19812011Caraba informinge21Male684Mid19832000Caraba informinge22Male684Mid19842001Caraba informinge23Male684Mid19842011Caraba informinge24Male642Severe20022024Caraba informinge25Famale524Mid19842011Caraba informinge26Male615Mid19842011Caraba informinge27Male623Severe20022024Caraba informinge28 | 9 | Male | 61 | 4 | Mild | 1999 | 2001 | Stroke |
| 11Male63Savare20202044Stroke13Male675Mild2002203Carabal infraction14Male455Mild20032003Carabal infraction15Famale631Severe19032003Carabal infraction16Famale631Severe19922000Carabal infraction17Famale631Severe19982010Stake18Male652Severe19982011Parkinsoi disese20Male652Severe19982010Carabal infraction21Male652Severe19982010Carabal infraction22Male652Severe19982001Carabal infraction23Male664Mild19992000Carabal infraction24Male666Mild19982001Carabal infraction25Fanale524Mild20022024Carabal infraction26Male642Severe19982001Carabal infraction27Male642Severe19982002Carabal infraction28Male643Severe19042002Carabal infraction29Male645Severe20012002Carabal infraction | 10 | Male | 56 | 2 | Severe | 2002 | 2003 | Spinal cord injury |
| 12 Fende 63 3 Severe 203 2004 Orestral Infraction 13 Male 67 5 Mild 2002 2002 Central Infraction 15 Fende 68 1 Sovere 203 203 Carboa Infraction 15 Fende 63 1 Sovere 1982 2000 Central Infraction 17 Fanale 71 3 Sovere 1988 2001 Central Infraction 18 Male 67 2 Sovere 1988 2001 Parkinos'n Solasse 20 Male 65 2 Sovere 1988 2001 Parkinos'n Solasse 21 Male 66 4 Mild 1933 2000 Central Infraction 22 Male 45 4 Mild 1938 2001 Contral Infraction 23 Male 45 4 Mild 1988 2001 Contral Infraction 24 Male 16 Mild 1988 2001 Contral Infraction | 11 | Male | 63 | 3 | Severe | 2002 | 2004 | Stroke |
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| 14 Mele 45 5 Mkl 2001 2002 Cerebral hemorrhage 15 Fenale 63 1 Sovere 1982 2030 Cerebral hemorrhage 17 Fenale 71 3 Sovere 1982 2001 Cerebral hemorrhage 17 Fenale 71 3 Sovere 1984 2010 Cerebral hemorrhage 18 Male 67 2 Sovera 1989 2010 Cerebral hemorrhage 19 Male 65 2 Sovera 1981 2010 Cerebral hemorrhage 21 Male 66 4 Mkl 1902 2000 Cerebral infraction 22 Male 66 4 Mkl 1989 2001 Cerebral infraction 23 Male 66 6 Mkl 1989 2001 Cerebral infraction 24 Male 61 2 Severe 1988 2010 Cerebral infraction 25 Fenale 54 2 Severe 1982 2002 Cerebral infraction 25 Male 52 Male 53 Severe 2012 2022 Cerebral infraction | 13 | Male | 67 | 5 | Mild | 2002 | 2003 | Cerebral infarction |
| 15Fende681Severe20032003Cerebral hemornage16Fende713Severe19922010Stroke17Fande713Severe19922010Carbaral hemornage18Male652Severe19982010Carbaral hemornage20Male652Severe19912010Carbaral hemornage21Male654Mild19032000Carbaral infarction22Male654Mild19332000Carbaral infarction23Male656Mild19932000Carbaral infarction24Male666Mild19932000Carbaral infarction25Fonda542Severe19882010Carbaral infarction26Male524Mild19902020Stroke27Male524Mild19902020Stroke28Male524Mild19902020Stroke39Male615Mild19912020Stroke30Male615Mild19922020Stroke31Male615Mild19922020Stroke32Male615Mild19922020Stroke33Male616Mild1992 <td>14</td> <td>Male</td> <td>45</td> <td>5</td> <td>Mild</td> <td>2000</td> <td>2002</td> <td>Cerebral hemorrhage</td> | 14 | Male | 45 | 5 | Mild | 2000 | 2002 | Cerebral hemorrhage |
| 16 Funde 63 1 Severe 192 200 Decktal hemorrhage 17 Fende 71 3 Severe 193 201 Barbale 18 Male 65 2 Severe 1938 201 Partinon's disease 19 Male 65 2 Severe 1938 201 Dearbal infraction 21 Male 66 4 Mild 200 Carebal infraction 22 Male 66 4 Mild 200 Carebal infraction 23 Male 66 4 Mild 200 Carebal infraction 24 Male 4 Mild 1939 200 Carebal infraction 25 Finade 47 2 Severe 2002 2002 Strake 26 Male 47 2 Severe 2002 2002 Carebal infraction 27 Male 61 5 Mild 1939 202 Strake 28 Male 62 Severe <td< td=""><td>15</td><td>Female</td><td>68</td><td>1</td><td>Severe</td><td>2003</td><td>2003</td><td>Cerebral hemorrhage</td></td<> | 15 | Female | 68 | 1 | Severe | 2003 | 2003 | Cerebral hemorrhage |
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| A4 Made D0 D Mind 1998 2000 Categorian indiction 25 Fendle 54 2 Severe 2002 2010 Categorian indiction 26 Male 47 2 Severe 2002 2002 Categorian indiction 27 Male 52 4 Mild 2002 2002 Categorian indiction 28 Male 51 5 Mild 1988 2002 Stroke 29 Male 61 5 Mild 1986 2001 Categorian indiction 20 Male 61 5 Mild 1986 2001 Categorian indiction 31 Male 62 4 Mild 2001 2002 Stroke 33 Male 62 4 Mild 1972 2001 Tategorian indiction 34 Male 56 4 Mild 1972 2002 Cateboria indiction 35 <td>24</td> <td>Malo</td> <td>40</td> <td>4</td> <td>Mild</td> <td>1000</td> <td>2004</td> <td>Corobral information</td> | 24 | Malo | 40 | 4 | Mild | 1000 | 2004 | Corobral information |
| Add Fernale 3-4 2 Severe 13-8 2001 Control Inflaction 26 Male 52 4 Mild 2002 Stroke 27 Male 53 3 Severe 2002 2022 Cerebral Infraction 28 Male 61 5 Mild 1936 2002 Stroke 30 Male 68 4 Mild 1936 2011 Cerebral hemorrhage 31 Male 68 4 Mild 1936 2011 Cerebral hemorrhage 32 Male 68 4 Mild 2001 2002 Stroke 34 Male 64 2 Severe 2001 2002 Stroke 35 Female 62 4 Mild 1972 2000 Traumatic cerebral hemorrhage 36 Male 70 4 Mild 1934 2001 Cerebral hemorrhage 37 Male 70< | 24 | Fomalo | 54 | 2 | Sovero | 1999 | 2000 | |
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| 50Male571Severe20002002Cerebral infarction51Female421Severe20002001Cerebral hemorrhage52Male351Severe20002003Cerebral hemorrhage53Male683Severe20012004Cerebral infarction54Male682Severe19972003Cerebral infarction55Male642Severe19812003Cerebral hemorrhage56Male631Severe19961997Cerebral hemorrhage57Male831Severe19902000Stroke | 49 | Female | 68 | 1 | Severe | 2000 | 2001 | Cerebral infarction |
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| | | Treatment for causal diseases and sequelae | Treatment for functional pre | servation and improvement |
|--------|---|---|---|--|
| | | Medical intervention and operation (A) | Assistive devices (B) | Rehabilitation therapy (C) |
| Step 1 | Necessity' Ves No No | A1. Is treatment for the secondary prevention (of high blood pressure, hyperlipidemia, stroke, and cardiovascular disease) necessary? A2. Does the patient complain of pain limiting activities of daily living? A3. Does the patient have muscle contraction limiting activities of daily living? A4. Does the patient currently have a pressure ulcer or has one developed in the last three months? 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) A6. Does the patient have severe spasticity limiting activities of daily living? A8. Has the patient undergone bronchotomy (respiratory care)? | B1. Cases where muscle strength of the ankle is less than 50%, toe clear- ance is not possible during ambulation, or moving left and right is not possible (ankle-foot orthosis) B2. Cases where there is contracture of the hand (wrist and hand orthosis) B3. Cases where muscle strength of the shoulder is less than 50% and subluxation of the cartilage (arm sling) B4. Cases where where is a lack of stability in ambulation (walking aids: cutch, cane, walking cannot be performed independently (manual wheelchair with or without reclining back) B6. Cases where contrive abilities are proficient enough to operate a mobile vehicle as well as to maintain one handed function, and move- ment of long distance is needed (power wheelchair or scooter) | C1. Cases where there is a progression of joint contracture or paralysis (range of motion and muscle strengthening exercise) C2. Cases where ambulation cannot be performed independently (ambula- tion exercise) C3. Cases where there is paralysis and contracture of the upper extremity (functional training of the upper extremities - occupational therapy) C4. Cases where activities of daily living are dependent on others (activities of daily living exercise) C5. Cases where there is a limitation in activities of daily living due to therapy) C5. Cases where there is a limitation in activities of daily living due to cognitive and perceptual disabilities (cognitive therapy) C3. Cases where a normal diet is inadequate due to dysphagia (dysphagia management) |
| Step 2 | Appropri- ateness ² ateness ² AP B AP B NA | Medication and medical treatment regarding A1 is received on a regular basis by a physician specialist. A treatment of medications, injections, or physical therapy regarding A2 is being received at a medical facility. A treatment of physical therapy, orthosis, or surgery regarding A3 is being received at a medical facility. A treatment of physical therapy, orthosis, or surgery regarding A3 is being received at a medical facility. Fortenssional medical facility treated and are cared for by a reagvires. Fortenssional medical facility treated and are cared for by a reagvires. Regular unination and cleanliness (A6) is sustained by caregivers 7. Medication, RDM exercise, or injection treatment regarding A7 is received through a physician's prescription Cleanliness and regular replacement regarding A8 is being maintained | Ankle-foot orthosis is prescribed by a medical facility in cases of B1 2. Wrist and hand orthosis is prescribed by a medical facility in cases of B2 3. The arm is being sustained by an arm sling in cases of B3 4. Walking also prescribed by a physician are used in cases of B4 5. A wheelchair is retained in cases of B5 6. The power wheelchair or scooter is retained by the physician's diagnosis and prescription in cases of B6 | Regular treatment is received, or contracture is prevented by an assistive device in cases of C1 The patient's improvement in ambulation is expected by treatment in cases of C2 The aptient's improvement in ambulation is expected by treatment in tive device in cases of C3 The aptient 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 The patient receives treatment on learning new ways of communication through education in cases of C4 The patient receives treatment when improvement in cognitive function is expected in cases of C8 Displayed in cases of C8 Displayed in cases of C8 Displayed as amination is received from a medical facility, and diretary modification or swallowing therapy is provided in cases of C7 |
| | | | Regular follow-up | |
| | | Intensive management | Regular n | nanagement |
| Step 3 | Necessity Yes | A regular check-up is needed at least once every 1-2 mont | hs A regular check-up is neede | d at least once or twice every year |
| | □ No | Less than 1 year after the onset diseases resulting in the | e disability | |
| | Appropriater | less 3 \square When management of diseases resulting in the disabili | y is necessary | |
| | 🗆 AP | When medication is necessary | | |
| | □ Ib | When intensive management of | | |
| | D NA | spasticity or other complications is necessary | | |

□ AP

Final Appropriateness

Step 4

AP, appropriate; IP, inappropriate; NA, non-applicable. ¹Doctors checked whether it was necessary or not, as well as whether a patient had received it or not. ²Doctors checked one of three response options, AP, IP, or NA, as compared to their prior evaluation results from step 1. ³Doctors checked one of three response options, AP, IP, or NA, as compared to their prior evaluation results from step 1.

□ Ib

Table 3. Unmet needs of persons with brain disorders

| Category | AP (A) | IP (B) | NA (C) | Total ¹ (D) | Need ² (E) | AR ³ (F) | Unmet need⁴ (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.

¹Total (D) = A+B+C+D.

 2 Need (E)=(A+B)/D × 100.

 $^{3}AR(F) = A/(A+B) \times 100.$

 4 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 | <i>p</i> -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

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

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 internal) for understanding their needs for earlier medical intervention as well as social services to support their medical treatments.

social services, physical therapy, assistive devices, and day care

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 exJournal of Preventive Medicine & Public Health

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 α 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-

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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.

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CONFLICT OF INTEREST

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

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