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Identification of Hemodialysis Patients' Physical and Psychosocial Problems Using the International Classification of Functioning, Disability and Health (ICF)

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1. Introduction

We aimed to identify hemodialysis (HD) patients' physical and psychosocial problems using the International Classification of Functioning, Disability and Health (ICF)-based checklist we developed. The ICF belongs to the WHO's family of international classifications, and it is the instrument for comprehensive understanding of patients. HD patients have diverse physical and psychosocial problems, and ICF-based approach may be useful to improve management and quality of life (QOL) of patients on HD. In this article, we introduced the new data associated with physical and psychosocial problems of 222 patients in HD, which extends our previous report (Tsutsui et al. 2009).

In Japan, the number of patients on HD was 36,397 in 1980 and increased to 290,675 in 2009 (Patient Registration Committee, Japanese Society for Dialysis Therapy, 2010). In addition to the physical limitations in functioning caused by renal failure and its comorbidities, HD patients have various restrictions resulting from HD therapy requiring radical lifestyle changes. Therefore, HD patients tend to have both physical and psychosocial problems. Thus, evaluation of QOL is especially important, and the Kidney Disease Quality of Life (KDQOL™) (Hays et al, 1994) and the Kidney Disease Quality of Life-Short Form (KDQOL-SF™) (Hays et al, 1994) have been widely used. The KDQOL-SF™ includes multi-item scales targeted at the particular health-related concerns of individuals who have kidney disease and are on dialysis. In the present study, we aimed to investigate the use of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), which is the instrument for comprehensive understanding of patients. In addition to evaluate physical and psychosocial problems of patients, ICF can be used as a tool for team medical treatment to make plans for treatment and care of patients. We have reported the checklist for HD patients based on ICF (Tsutsui et al. 2009). The data in this article include those of patients on HD with diabetic nephropathy, which was excluded in the previous report.

2. International classification of functioning, disability and health

The ICF was published by the World Health Organization (WHO) in 2001 to standardize descriptions of health and disability. The ICF and International Classification of Disease-10th

Revision (ICD-10) constitute the core classification in the WHO’s family of international classifications, which provides a valuable tool to describe and compare the health of populations in an international context. The information on mortality (provided by ICD-10) and on health outcomes (provided by ICF) may be combined in summary measures of population health.

The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states. It defines components of health and some health-related components of well-being (such as education and labor). An ICF-based approach can also be useful to collect information on a broad set of impairments, activity limitations and environmental factors that contribute to improve or worsen patients’ functioning and disability status. Such information could provide a common framework for research, clinical work and social policy and help in improving the identification of needs related to health and social services, and related interventions.

The ICF provides a description of situations about human functioning and its restrictions and serves as a framework to organize this information. The ICF is based on the biopsychosocial model, an integration of medical and social models. The patient’s functioning is conceived as a dynamic interaction between the underlying health condition and specific personal and environmental factors. The following diagram is one representation of model of disability that is the basis for ICF (Figure 1).

Fig. 1. Interactions between the components of ICF (WHO, 2001)

The ICF organizes information in the two main subdivisions: Part 1 covers functioning and disability and Part 2 covers contextual factors. Each of these two parts is divided into components. Components of functioning and disability consist of "Body functions and structures" and "Activities and participation". Components of contextual factors consists of

"Environmental factors" and "Personal factors". "Body functions" relate to the physiological and psychological functions of the body. "Body structures" are anatomic parts of the body such as organs, limbs and their components classified according to body systems. "Activities" is the execution of a task or action by an individual. It represents the individual perspective of functioning. "Participation" is a person's involvement in a life situation. It represents the societal perspective of functioning. "Environmental factors" refer to all aspects of the external or extrinsic world that form the context of an individual's life such as social attitudes and values, social systems and services, policies, rules and laws. "Personal factors" are those related to the individual such as age, gender, social status, and life experiences, which are not currently classified in ICF, although users may incorporate in their applications of the classification (WHO 2001).

Every component of the ICF has a hierarchical structure. The categories of ICF are classified by the code in which the letters (b, s, d, and e) is combined with the number. The letters b, s, d and e refer to the components "Body functions" (b), "Body structures" (s), "Activities and participation" (d), and "Environmental factors" (e). The letters are followed by a numeric code that defines the chapter number (first digit) and the category levels up to the fourth level (suffix of two, three, or four digits).

2.1 ICF checklist

The ICF in its current version consists of 1424 codes. Therefore, it is necessary to select a subset of the codes as needed for any given purpose. One of such activities is the development of the ICF checklist (WHO, 2003). The ICF checklist consists of a selection of 128 first- and second-level categories from the whole ICF classification system. It provides a relatively simple-to-use questionnaire, and is a generic template for a structured interview. The ICF checklist makes it possible to generate a profile of the individual patient on the functioning and disability in clinical practice. Of the 128 categories, 32 belong to "Body functions", 16 to "Body structures", 48 belong to "Activities and participation", and 32 to "Environmental factors". The ICF checklist utilizes a "qualifier" to evaluate each component, which is considered to be positive when patients have any level of impairments (i.e. mild, moderate, severe, or complete) in "Body functions" and "Body structures"; any level of activity limitations or participation restrictions in "Activities and participation"; and any level of barrier in "Environmental factors" (WHO 2003, Ewert et al. 2004).

2.2 ICF core sets

The ICF core sets are developed for medical conditions that have high impact on a patient's functioning and disability (Stucki et al. 2002). They have been developed in a formal decision making and consensus-based process integrating evidence gathered from studies for chronic conditions (Weigl et al. 2004, Brockow et al. 2004, Ewert et al. 2004). The ICF core sets for patients with a determined health condition represent a selection of ICF categories out of the whole classification that can serve as minimal standards for reporting of functioning and health for clinical studies and clinical encounter or as standards for multiprofessional. The ICF core sets contain categories not only on anatomic and pathophysiologic changes but also on functioning in every-day activities and relevant environmental factors.

These ICF core sets are to be developed in two levels: A brief and comprehensive ICF core sets. The brief ICF core sets includes only the most important ICF-categories and is intended to be rated in all patients of a clinical study. However, the comprehensive ICF core sets

include all categories that are typically limited in the selected health condition, and are created to guide multidisciplinary assessment (Stucki et al. 2002). The ICF core sets have been developed for many health conditions including diabetes mellitus (Ruof et al. 2004), obesity (Stucki et al. 2004), and stroke (Geyh et al. 2004).

3. Identification of HD patients’ physical and psychosocial problems

The process of developing the checklist for the HD treatment is briefly described. Initially, we interviewed 32 HD patients using ICF checklist. They were interviewed for each category of the ICF checklist whether they had problems since starting HD treatment. For example, in the category of *b134 Sleep*, patients were interviewed “Have you ever experienced insomnia, nocturnal awakening, or hypersomnia since starting HD treatment?” The interviewer questioned about the details of their problems when patients answered “yes”. The interview was done by the first author who was the medical social worker. All categories that at least 1 patient reported a problem were selected as problem categories. As a result, 57 categories of the ICF checklist were selected for the checklist for the HD treatment. Thirty-five categories in the ICF that were not included in the ICF checklist were chosen based on the consensus of the conference that included physician, nurses, and medical social worker. These 92 categories consisted of 39 categories from the “Body functions” component, 13 from the “Body structures” component, 20 categories from the “Activities and participation” component, and 20 categories from the “Environmental factors” component. Finally, we added 8 categories that are not included in the ICF categories considering the specificities of HD. These categories are following; *Functions of vascular access* in “Body functions” component, *Vascular access* in “Body structures” component, *Going to hospital*, *Managing weight*, *Angiostasis by oneself after drawing out needle*, and *Preparing a dialysis diet* in “Activities and participation” component, *Dialysis professionals* in “Environmental factors” component. Taken together, the checklist for the HD comprises 100 categories.

	Body Functions	Body Structures	Activities and Participation	Environmental Factors	Total
ICF checklist Version2.1a	19	8	15	15	57
Additional ICF categories for HD	20	5	5	5	35
Categories specific for HD	1	1	5	1	8
Final Checklist for HD	40	14	25	21	100

Table 1. Component of checklist.

3.1 Physical and psychosocial problems of maintenance HD patients

We interviewed 222 maintenance HD patients using the checklist for HD patients. The characteristics of them are shown in Table 2.

3.1.1 Body functions

The percentage of patients on maintenance HD who reported problems in each category of “Body functions” component is described in Table 3.

	Total n=222
Sex (men/women)	152/70
Age (years)	61±11
Age of HD introduction (years)	52±13
Duration of HD (years)	9.1±8.0
Underlying disease	
Diabetic nephropathy	86
Chronic glomerulonephritis	46
Nephrosclerosis	44
Polycystic kidney	9
Gouty kidney	6
Interstitial nephritis	2
Obstructive urinary disorder	2
Reflux nephropathy	1
Cystinuria	1
Pregnancy-induced kidney disease	1
Pyelonephritis	1
Systemic lupus erythematosus	1
Unidentified	22

Table 2. Maintenance HD patients' characteristics.

Body Functions	%
b110 Consciousness functions	25.7
b1300 Energy level	39.2
b1302 Appetite	26.6
b134 Sleep functions	46.4
b140 Attention functions	32.9
b152 Emotional functions	26.6
b210 Seeing functions	50.9
b240 Sensations associated with hearing and vestibular function	37.8
b250 Taste function	20.7
b260 Proprioceptive function	36.9
b265 Touch function	16.7
b270 Sensory functions related to temperature and other stimuli	12.2
b280 Sensation of pain	45.9
b410 Heart functions	45.9
b415 Blood vessel functions	22.5
§ Functions of vascular access	27.2
b420 Blood pressure functions	75.7
b430 Haematological system functions	14.0
b440 Respiration functions	26.6
b4550 General physical endurance	50.5

Body Functions	%
b4551 Aerobic capacity	45.9
b4552 Fatigability	57.2
b515 Digestive functions	24.8
b525 Defecation functions	51.4
b530 Weight maintenance functions	22.5
b535 Sensations associated with the digestive system	33.8
b545 Water, mineral and electrolyte balance functions	26.6
b555 Endocrine gland functions	14.0
b610 Urinary excretory functions	61.3
b620 Urination functions	47.7
b64 Sexual functions	18.0
b670 Sensations associated with genital and reproductive functions	12.6
b710 Mobility of joint functions	43.2
b730 Muscle power functions	12.6
b735 Muscle tone functions	40.5
b780 Sensations related to muscles and movement functions	64.4
b810 Protective functions of the skin	59.9
b820 Repair function of the skin	36.9
b840 Sensation related to the skin	74.8
b850 Functions of hair	29.7

§: Categories specific for HD (Not ICF categories)

Table 3. Percentage of maintenance HD patients who reported impairment in each category of “Body functions” component.

In the “Body functions” component, problems of patients on maintenance HD are associated with sleep, fatigue, defecation, blood pressure, urination, muscle, skin, and those related to the symptoms or complication of kidney disease. Itching of the skin (Danquah et al. 2010, Caplin et al. 2011), sleep (Čengić et al. 2010, Danquah et al. 2010), blood pressure (Van Buren et al. 2011, Caplin et al. 2011), muscle cramps (Danquah et al. 2010, Weisbord et al. 2008), and constipation (Wu et al. 2004, Yasuda et al. 2002) have been reported as significant problems in patients with maintenance HD. According to the interview, these patients tend to have problems such as itching, muscle cramp, or low blood pressure not only in everyday life but also during HD treatment, which seem worry them substantially.

3.1.2 Body structures

The percentage of maintenance HD patients who reported problems in each category of component of “Body structures” component is described in Table 4. In the “Body structures” component, a high percentage of patients on maintenance HD reported problems related to nail, disorder of urinary system, and eye disease. Disorder of nail structure such as half-and-half nail and tinea unguium (Saray et al. 2004, Dyachenko et al. 2007), disorder of urinary system such as pyuria and loss of urination (Vij et al. 2009, Fasolo et al. 2006), and eye disease such as diabetic retinopathy and glaucoma (Chiu et al. 2008, Varbec et al. 2005) have been reported.

Body structures	%
s220 Structure of eyeball	41.0
s410 Structure of cardiovascular system	30.2
s4100 Heart	9.5
§ Vascular access	33.8
s550 Structure of pancreas	0.9
s5801 Thyroid gland	12.1
s5802 Parathyroid gland	14.7
s610 Structure of urinary system	61.3
s6100 Kidneys	100.0
s630 Structure of reproductive system	6.8
s730 Structure of upper extremity	28.4
s750 Structure of lower extremity	13.5
s770 Additional musculoskeletal structures related to movement	5.0
s830 Structure of nails	56.3

§; Categories specific for HD (Not ICF categories)

Table 4. Percentage of maintenance HD patients who reported impairment in each category of “Body structures” component.

3.1.3 Activities and participation

The percentage of maintenance HD patients who reported restrictions in each category of “Activities and participation” component is described in Table 5.

In the “Activities and participation” component, a high percentage of patients reported restrictions related to actions that use upper limbs, job, and hobby. Consistently, actions that use upper limbs (Tander et al. 2007, Namazi et al. 2007), job (Panagopoulou et al. 2009, Kutner et al. 2010), and hobby (Al Eissa et al. 2010) have been reported to be highly restricted. The time restriction due to the regular dialysis and the need to protect vascular access seem to be major factors to affect patients’ restriction in activities and participation.

3.1.4 Environmental factors

The percentage of maintenance HD patients who reported barriers in each category of “Activities and participation” component is described in Table 6.

In the “Environmental factors” component, a high percentage of paients reported as barriers in categories related to transportation service, social security, and labor. Transportation (Diamant et al. 2010, Gorden et al. 2003), social security such as medical fee (Holley et al. 2006, Gracia-Gracia et al. 2005) and labor (Neri et al. 2009, Muehrer et al. 2011) have been reported as barriers. Maintaining employment is one of the most serious problems. We reported that 41% of the patients in the previous study (Tsutsui et al, 2009) were terminated, transferred to a different position, demoted, or changed their employment agreement (from

Activities and Participation	%
d220 Undertaking multiple tasks	14.0
b240 Handling stress and other psychological demands	17.1
d430 Lifting and carrying objects	35.1
d440 Fine hand use	23.0
d450 Walking	13.1
d465 Moving around using equipment	9.9
d470 Using transportation	15.8
d475 Driving	19.4
§ Going to hospital	5.4
d510 Washing oneself	9.9
d520 Caring for body parts	9.5
d550 Eating	7.2
d570 Looking after one's health	15.8
§ Managing weight	14.0
§ Confirmation of vascular access	0.5
§ Angiostasis by oneself after drawing out needle	9.9
d630 Preparing meals	7.2
§ Preparing a dialysis diet	17.1
d640 Doing housework	9.5
d660 Assisting others	2.7
d845 Acquiring, keeping and terminating a job	24.8
d850 Remunerative employment	21.6
d9201 Sports	18.5
d9204 Hobbies	32.0
d9205 Socializing	24.8

§; Categories specific for HD (Not ICF categories)

Table 5. Percentage of maintenance HD patients who reported restrictions in each category of “Activities and participation” component.

full-time to part-time employment). According to Japanese statistics, 37.7% of men HD patients and 43% of women HD patients were terminated or retired in the past 5 years (Japan Association of Kidney Disease Patients, Japanese Association of Dialysis Physician. 2007). The problem related to the payment of medical fees is another serious concern for patients. Patients on HD had received a total exemption of medical fees until the coming into force of the "Law for Independence of Persons With Disabilities“ in 2006. According to a report (Japan Association of Kidney Disease Patients, Japanese Association of Dialysis Physician. 2007), 75.2% of Japanese HD patients greatly hope for “continuation of medical security of HD treatment“.

Environmental Factors	%
e110 Products or substances for personal consumption	27.5
e310 Immediate family	8.1
e320 Friends	7.7
e325 Acquaintances, peers, colleagues, neighbors and community members	5.0
e330 People in positions of authority	5.9
e350 Domesticated animals	14.4
e355 Health professionals	16.7
§ Dialysis professionals	5.4
e410 Individual attitudes of immediate family members	4.1
e420 Individual attitudes of friends	4.1
e425 Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	6.3
e430 Individual attitudes of people in positions of authority	3.6
e440 Individual attitudes of personal care providers and personal assistants	2.3
e450 Individual attitudes of health professionals	18.5
e465 Social norms, practices and ideologies	17.1
e540 Transportation services, systems and policies	10.4
e555 Associations and organizational services, systems and policies	14.9
e560 Media services, systems and policies	23.4
e570 Social security services, systems and policies	23.8
e580 Health services, systems and policies	32.4
e590 Labour and employment services, systems and policies	35.1

§: Categories specific for HD (Not ICF categories)

Table 6. Percentage of the maintenance HD patients who reported barriers in each category of “Environmental factors” component.

4. Conclusion

We developed the ICF-based checklist for the HD treatment, and identified the physical and psychosocial problems that the HD patients had. We showed the features of HD patients with problems associated with disease or impairments as well as daily life activities. The checklist based on ICF, which is an integrated model of the medical and the social models, enables us to understand HD patients comprehensively. We will continue efforts to identify more relevant ICF categories to complete the final version of the checklist.

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