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## Research Article

# Change in Care Dependency of Stroke Patients: A Longitudinal and Multicenter Study



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## SUMMARY

**Purpose:** The study was conducted to investigate the change of care dependency in stroke patients from inpatient wards and outpatient units in Indonesia.

**Methods:** This study is longitudinal and multicentered. One hundred and nine patients were included from four hospitals on the island of Java. Care dependency was assessed using the Indonesian version of the 15-item Care Dependency Scale (CDS) at five points in time: at inpatient wards for admission and discharge and at outpatient units after discharge in the 1st week, the 5th week, and the 13th week.

**Results:** Most of the patients were male (65.1%), and diagnosed with ischemic stroke (71.5%). The results showed that care dependency in stroke patients decreased significantly from admission to discharge, as well as from the 5th to the 13th week as measured by the CDS. At admission, 23.0% of the patients were completely dependent on care, and at the 13th week about 1.0% were. Patients' care dependency decreased significantly in all care dependency items of the CDS in the inpatient ward, but five care dependency items of the CDS did not significantly decrease in the outpatient unit.

**Conclusions:** Based on the findings of this study, we recommend that hospital-based and community-based services should include continual care dependence monitoring using this comprehensive instrument. Care dependency is subject to change over time, therefore nurses have to plan and tailor adequate nursing care measures to patient needs in the different stages, especially with respect to the aspect of mobility.

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## Introduction

Stroke is a serious worldwide problem both in high-income and low-income countries. According to the World Health Organization, it is one of the four main types of noncommunicable diseases (NCDs or diseases that are not passed from person to person). In 2012, stroke was the leading cause of death in the world, with as many as 6.7 million deaths [1]. A report of NCDs from an Indonesian hospital in 2009 mentioned stroke as a disease with the highest case fatality rate (12.6%) [2]. Stroke prevalence in Indonesia in 2007 was 0.8% and increased to 1.2% in 2013 [3]. In 2010, in Indonesia, stroke was the number one killer, causing 15.4% of all deaths [4].

Stroke is an acute neurological disorder resulting in long-term neurological consequences and disability [5]. These problems are

associated with immobilization, speech disturbances, impaired cognitive function, depression, and incontinence [5–7]. Stroke is one of the principal reasons for dependency on nursing care among adults [8], and the consequences result in continued care dependency [9] and also affect socioeconomic and cultural activities in most patients [5,10]. Andrew et al. reported that the majority of poststroke patients experienced some unmet needs and required assistance to perform daily living activities [11].

Care dependency in individuals is related to the fulfillment of basic human needs such as physical, mental, emotional, cognitive, social, economic, and environmental needs [12]. Assessment of the patients' degree of dependency is essential in determining nursing care needs, planning nursing intervention, helping increase patients' abilities, and creating proper discharge plans. Moreover, assessing the degree of functional limitation at admission will help nurses predict the functional outcome after rehabilitation [13,14]. A study has shown that the degree of care dependency using the Barthel index after a stroke was higher compared to before the

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stroke [15]. However, the Barthel index contains 10 items that are only based on physical characteristics.

Only a few studies have reported the degree of care dependency among stroke patients in a comprehensive way. The activities of daily living are frequently used and recommended as good outcome indicators of stroke care [10,13,15,16]. However, those studies describe only one aspect of care dependency; hence, a broader concept of dependency is needed for better assessment.

In Indonesia, the evidence of changes in care dependency from hospital admission to outpatient visits using a standardized assessment in stroke care is lacking. In fact, almost all stroke patients return to their homes because an inpatient rehabilitation center is unavailable. Stroke patients follow a care plan that starts at the hospital and which focuses on acute care. On the inpatient ward, nurses play important roles in that they stabilize their patients' vital signs, provide fluid, monitor the intake of nutrition, manage the patient's ability to perform activities of daily living and prepare the patients and their families for discharge planning [17].

After discharge from the hospital, patients return to their home and go to the hospital's outpatient unit as part of chronic care. Patients go to the outpatient unit 1 week after discharge, and then make monthly visits. In the outpatient unit, patients receive medical attention, physical rehabilitation, and nursing care. The outpatient unit nurse assesses the patient, provides nursing care, provides attention and support in terms of medical and rehabilitation therapy programs and consults with a multidisciplinary team [17]. One of nursing care activities conducted in outpatient unit is health education, which encourages the patients to exercise the highest level of independence possible [17]. Furthermore, family members who are responsible for daily caregiving are offered support and education through the outpatient follow-up program.

This study is the first investigation using a comprehensive instrument, namely the Care Dependency Scale (CDS), to assess stroke patients in Indonesia. The purpose of this study was to investigate, changes in care dependency at admission, at discharge, and during visits of the stroke patients to outpatient units in Indonesian hospital settings. In addition, in our study the changes in the patients' levels of care dependency according to CDS items were explored during inpatient and outpatient care.

## Methods

### Study design

The study was a longitudinal and multicenter investigation. The data were collected by trained nurses in the hospitals at five measurement points starting at inpatient units upon admission as baseline data (T0), discharge (T1), and follow-up visits at outpatient units in the 1st week after discharge (T2), the 5th week after discharge (T3), and the 13th week after discharge (T4).

### Setting and samples

Data collection took place on Java Island, which has the largest (57.0%) population in Indonesia. Five public hospitals were invited to participate via post mail, and four participated. A convenience sampling from four large public general hospitals located in four different provinces was performed. Inclusion criteria were stroke patients at 21 years of age or greater who had been diagnosed with ischemic stroke or hemorrhagic stroke based on computed tomography scan imaging. Patients with transient ischemic attack and subarachnoid hemorrhagic stroke were excluded.

We expected an effect size of .25 with two-sided 5% significance level and 80% power, a sample size of 125 was necessary. We anticipated an attrition rate of 10.0%, which led to a sample size of

138 patients. The response rates (T0, T1, T2, T3, and T4) were between 94.2% (T1) and 78.9% (T4). We lost 29 data points: 8 patients died in inpatient wards, 11 patients were referred to the district hospital and 10 patients did not visit the outpatient unit again for unknown reasons. No patients refused to participate further in our study. In total, the study investigated five inpatient stroke wards and four outpatient units with 109 participants.

### Measurements

Care dependency of each patient was assessed using the Indonesian version of the CDS [18], which was originally developed in the Netherlands to assess care dependency in residents with dementia [19]. The care dependency scale is based on Virginia Henderson's nursing model and is a framework of human needs [19]. The CDS contains 15 items, including physical and psychosocial aspects and, therefore, can be comprehensively used to determine the participants' care dependency levels. The psychometric properties of the CDS have been well-tested in pressure ulcer patients in Indonesia. The Indonesian version of the CDS had an interrater reliability of .88 with an exact interrater agreement of 45.0% [18]. It showed very good reliability, and the nurses were able to use it for the assessment of care dependency [18]. The reliability analysis of CDS in the current study yielded a Cronbach  $\alpha$  of .98 from inpatient data and .97 from outpatient data. The Kappa values were between .71 to .87 from inpatient data and between .68 to .78 from outpatient data.

The CDS was assessed using a 5-point Likert scale. Between 15 and 75 points per patient were generated. According to Dijkstra et al [19], patients with sum scores of 15–24 are classified as “completely care dependent”; 25–44, as “to a great extent care dependent”; 45–59, as “partially care dependent”; 60–69, as “to a limited extent care dependent”; and 70–75, as “almost care independent”. A cut-off point of 68 is considered to be the threshold for care dependency [20]. The CDS is easy to use and quick, requiring approximately 5 minutes [19], and can be used safely for international comparisons of care dependency [21].

The data on age, gender, stroke subtypes, and comorbidity conditions were collected at admission. Stroke subtypes and comorbidity conditions were recorded from the patients' medical records. Comorbidity conditions were diagnosed by the physician as the presence or absence of one or more additional diseases or disorders co-occurring with the stroke.

### Data collection

The head of the nursing department chose the team of raters based on their levels of experience (> 3 years in stroke care) and the availability of nurses from these wards on the day of measurement. Forty-five nurses participated in a 2-hour training session on using the CDS. The training was carried out in each hospital with the researcher (Nursiswati – Ns) as a facilitator. The nurses involved in the training agreed to modify recreational items into any leisure activities that provide entertainment for patients inside and outside the hospital. A trained rater team performed the assessments in a specific ward. Two trained nurses assessed every patient to increase the objectivity of measurement and minimize measurement errors. The study was conducted from October 2015 to May 2016.

### Data analysis

The data were analyzed using the statistical software SPSS, version 22 (IBM Corp, Armonk, New York, USA). The analysis was only performed on 109 completed data series from the respondents. A descriptive analysis was carried out to describe the characteristics of the patients and examine the CDS items. The

Wilcoxon-signed rank test and the Friedman test were used to compare means of care dependency from different time measurements. An alpha level of .05 was accepted as significant.

#### Ethical consideration

Ethical approvals were obtained from Medical University of Graz, University of Padjadjaran, and Soetomo Hospital (approval numbers 27-440 ex 14/15, 565/UN6.C1.32/Kep/PN/2015, and 589/Panke.KKE/XI/2015). Patients or their legal representatives, in case of unconscious patients, gave their written informed consent to participate in the study. Nurses assessed the level of consciousness by using, for example, the Glasgow Coma Scale. Only patients with full consciousness gave their own informed consent.

## Results

#### Sample characteristics

More than half of the patients were male and younger than 65 years, and mostly had been diagnosed with ischemic stroke. Many of them were referred from district hospitals without neurology specialization facilities. During admission (T0), the majority of patients were care dependent with an average score of care dependency of 44.85 (Table 1).

#### Changes in care dependency

Figure 1 shows the changes in care dependency over time. There was a decrease in the degree of care dependency from admission to discharge in the inpatient ward, and a stable status was observed when monitored in the outpatient unit up until the fifth week. Our findings showed that the mean score of the CDS at the 13th week was the highest or the least dependent with a total mean score of 58.03 ( $SD = 15.99$ ; Figure 1).

The results showed that the number of patients who remained care dependent was still high at the time point of the 13th week visit, with the majority being partially care dependent or to a great extent care dependent. Using the cutoff point revealed that a great proportion of the patients were care dependent. The Friedman test

conducted for repeated samples revealed a significant difference in the levels of care dependency from the time of admission up until the 13th week ( $p < .001$ ; Table 2).

Our results revealed that the levels of care dependency in stroke patients decreased significantly from T0 to T1, as well as from T3 and T4 ( $p < .001$ ). There was a significant change in care dependency over time ( $p < .001$ ).

#### Changes in care dependency items

Table 3 shows that, at T0, patients were the most care dependent in items of hygiene and getting dressed or undressed. At T4, the highest degree of care dependency was found in the items of mobility and getting dressed or undressed.

The scores of the patients decreased significantly in all care dependency items from T0 to T1; in the five CDS items, no significant decrease from T2 to T4 was observed. Patients were the most care dependent in terms of mobility in T1 as well as T4.

## Discussion

#### Changes in care dependency

The main aim of this study was to investigate the change in the degree of care dependency of stroke patients from the inpatient ward to the outpatient unit in Indonesian hospital settings over a period of 13 weeks. The results showed that care dependency in stroke patients decreased significantly from the time of admission to discharge, meaning that patients achieved good outcomes during the period of inpatient ward care. Based on the hospital standards, this period must be 1 week for patients who experienced an ischemic stroke and 2 weeks in those who experienced a hemorrhagic stroke. Furthermore, the nurse has an opportunity to optimize their nursing care to support the stroke patient and help them become less highly care dependent during this 1-week or 2-week period.

All in all, a significant change in care dependency was detected over time. This means that stroke patients are less care dependent in the 13th week after discharge. Kwakkel et al [13] explained that the process of spontaneous recovery was completed during a period of 6–10 weeks after stroke onset [13]. Furthermore, the

**Table 1** Stroke Patients' Characteristics at Hospital Admission ( $N = 109$ ).

Characteristics	Categories	No.	%	<i>M</i> ( <i>SD</i> )	Range
Age (yr)	< 65	69	63.3	60.33 (12.03)	27–88
	≥ 65	40	36.7		
Gender	Male	71	65.1		
	Female	38	34.9		
Stroke subtype	Ischemic	78	71.6		
	Hemorrhagic	31	28.4		
Comorbidity	No	55	50.4		
	Yes	54	49.6		
Kind of comorbidities	DM	18	33.3		
	CKD	2	3.7		
	CAD	5	9.2		
	HT	42	77.7		
Score of CDS				44.85 (20.59)	15–75
Degree of care dependency	Almost care independent	16	14.7		
	To a limited extent care dependent	19	17.4		
	Partially care dependent	25	22.9		
	To a great extent care dependent	23	21.1		
	Completely care dependent	26	23.9		

Note. CAD = coronary artery disease; CDS = Care Dependency Scale; CKD = chronic kidney disease; DM = diabetes mellitus; HT = hypertension.

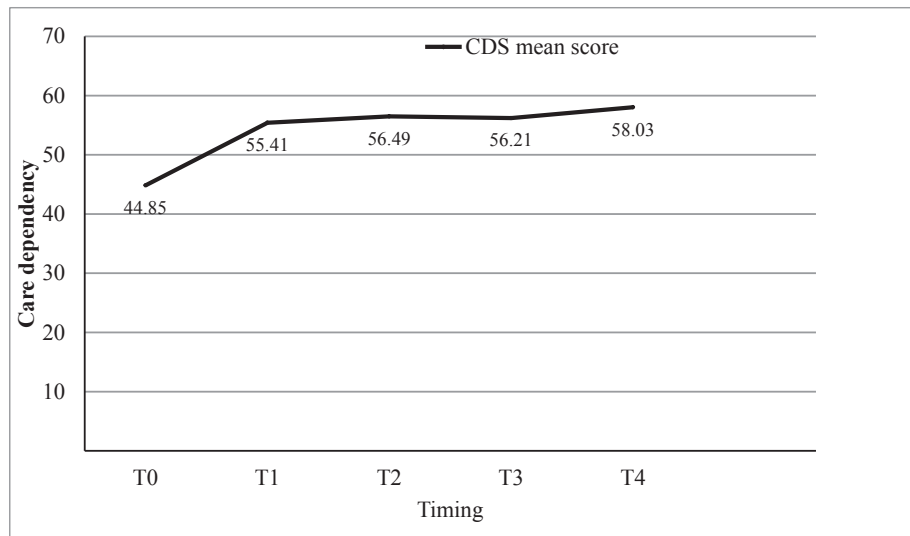


Figure 1. Changes in care dependency over time. Note. CDS = Care Dependency Scale; T0 = admission; T1 = discharge; T2 = the first week after discharge; T3 = the fifth week after discharge; T4 = the 13th week after discharge.

Table 2 Percentage of Patients Based on CDS Classifications Over Time (N = 109).

Time measurements	CDS categorization (original)					CDS (cutoff point)		p
	Almost care independent (%)	To a limited extent care dependent (%)	Partially care dependent (%)	To a great extent care dependent (%)	Completely care dependent (%)	Care independent (%)	Care dependent (%)	
T0	16 (14.7)	19 (17.4)	25 (22.9)	23 (21.1)	26 (23.9)	17 (15.6)	92 (84.4)	< .001
T1	35 (32.1)	17 (15.6)	30 (27.5)	19 (17.4)	8 (7.3)	35 (32.1)	74 (67.9)	
T2	30 (27.5)	20 (18.3)	33 (30.3)	25 (22.9)	1 (0.9)	36 (33.0)	73 (67.0)	
T3	31 (28.4)	18 (16.5)	36 (33.0)	23 (21.1)	1 (0.9)	34 (31.2)	75 (68.8)	
T4	35 (32.1)	17 (15.6)	37 (33.9)	19 (17.4)	1 (0.9)	37 (33.9)	72 (66.1)	

Note. CDS = Care Dependency Scale; T0 = admission; T1 = discharge; T2 = the first week after discharge; T3 = the fifth week after discharge; T4 = the 13th week after discharge.

Table 3 Change in Patients' Care Dependency According to Items During Inpatient and Outpatient Care.

CDS items	Time measurements						
	Inpatient ward		p	Outpatient unit			p
	T0 mean	T1 mean		T2 mean	T3 mean	T4 mean	
Eating/drinking	2.84	3.63	< .001 <sup>a</sup>	3.75	3.77	3.96	< .001 <sup>b</sup>
Continence	3.10	3.88	< .001 <sup>a</sup>	4.01	3.91	4.16	< .001 <sup>b</sup>
Body posture	3.00	3.77	< .001 <sup>a</sup>	3.85	3.81	3.90	.037 <sup>b</sup>
Mobility	2.72	3.41	< .001 <sup>a</sup>	3.55	3.48	3.58	.197
Day/night patterns	3.33	3.93	< .001 <sup>a</sup>	4.01	3.94	4.05	.137
Getting (un)dressed	2.65	3.43	< .001 <sup>a</sup>	3.52	3.52	3.62	.017 <sup>b</sup>
Body temperature	3.25	3.90	< .001 <sup>a</sup>	3.95	3.95	4.00	.280
Hygiene	2.55	3.47	< .001 <sup>a</sup>	3.57	3.55	3.65	.025 <sup>b</sup>
Avoidance of danger	2.92	3.61	< .001 <sup>a</sup>	3.63	3.66	3.74	.004 <sup>b</sup>
Communication	3.46	3.88	< .001 <sup>a</sup>	3.94	3.97	3.95	.323
Contact with others	3.34	3.96	< .001 <sup>a</sup>	4.00	3.94	4.04	.320
Sense of rules/values	3.33	3.93	< .001 <sup>a</sup>	4.00	3.87	4.12	.014 <sup>b</sup>
Daily activities	2.77	3.50	< .001 <sup>a</sup>	3.58	3.54	3.70	.007 <sup>b</sup>
Recreational activities	2.66	3.47	< .001 <sup>a</sup>	3.54	3.55	3.71	.002 <sup>b</sup>
Learning ability	2.88	3.57	< .001 <sup>a</sup>	3.59	3.54	3.77	.001 <sup>b</sup>

Note. CDS = Care Dependency Scale.

<sup>a</sup> Significant difference between T0 and T1.

<sup>b</sup> Significant difference between T2 and T4.

change in the levels of care dependency observed (i.e., that the patients were less dependent by the 13th week) may be related to the degree of care dependency at the time of hospital admission. Our results showed that some subjects had lower levels of care dependency upon the admission, that 14.7% were almost care

independent and 17.4% were care dependent to a limited extent. Moreover, the assessed severity of stroke at the time of admission strongly correlated to the outcome [10]. Based on our data, 71.6% of the patients had experienced an ischemic stroke and 50.4% had no comorbidities.

Although care dependency decreased from the time of hospital admission up until the 13th week after discharge, care dependency remained stable at some points in time, namely, from the time of discharge to the 1st week after discharge and from the 1st week to the 5th week. These reported changes in care dependency that occur up until the 13th week will encourage family members and skilled community nurses to take active roles and offer essential care programs [10].

In this study, the CDS was used to measure care dependency. Other investigations that used different measurements to detect care dependency had similar results. For example, Kwakkel et al [13] measured care dependency using the Barthel index and found a decrease in the first week after hospital admission in stroke patients in the Netherlands. Pemila et al [22] also investigated Indonesian stroke patients from the time of discharge to the fourth week after discharge and, as in our study, found no differences in the Barthel index scores. Moreover, using the Chinese Barthel Index and Instrumental Activities of Daily Living Scale, one study showed performance improvements in stroke patients during the first 3 months after discharge [23].

The CDS was used to measure the levels of care dependency in cases of heart failure [24], which is similar to stroke as a non-communicable diseases. Patients with noncommunicable diseases, known as chronic diseases, need continual medical monitoring and nursing care. No significant differences in the degrees of care dependency 3 months after hospital admission were found in the population of interest [24].

#### *Change in care dependency items*

The highest degree of care dependency was found in the item mobility at the time of discharge and in the 13th week after discharge. Mobility is closely connected with activities of daily living and physical rehabilitation after a stroke [25]. Mobility also was reported by 80.0% of participants in a study from Denmark as problematic after stroke [26]. Mobility was not significantly different from the 1st week to the 13th week. This finding is comparable with the findings of another study [15] that showed that patients were more care dependent in mobility activities at admission, and the ability to go to the tub/shower remained the most care dependent activity at discharge.

According to representatives of health system services in Indonesia, stroke patients must continue their rehabilitation program in outpatient units to improve their functional ability and quality of life by receiving physical and psychosocial therapy. Therefore, it is important to consider the degree of care dependency at discharge in order to plan a continuing rehabilitation program. This study highlights some care dependency items that must be prioritized when designing and applying discharge planning. Nurses must teach family members to play important roles and help increase the independence of the patient in terms of their mobility, day/night patterns, body temperature, communication and contact with others.

Overall, using the CDS allows researchers to gain an illustration of changes in the degree of dependency experienced by stroke patients. This will help nurses plan and implement better stroke care. CDS should be considered as a therapeutic measurement; it should be used to improve treatment outcomes and help maintain the quality of life of stroke survivors [10]. The results of this study are highly encouraging because nurses are given a broader range of information on nursing care needs that will enable them to make more accurate assessments. This study increases knowledge about physical and psychosocial care dependency and allows the design of nursing interventions that can appropriately address the needs of stroke patients. Understanding nursing care problems is vital to

determining actual and realistic nursing care plans. However, it is valuable for Indonesian healthcare providers to be concerned with the creation of better continual community care programs.

There are two limitations that must be considered when interpreting these results. The cutoff point in Dijkstra et al.'s study [20] that allows the determination of whether a patient is dependent on nursing care was used in this study. Dijkstra et al determined this cutoff point in the study conducted to investigate a broader range of chronic illnesses [20]. It cannot be taken for granted that this is the best cutoff point for the stroke patient. Therefore, the given cutoff point was considered to apply to the specific study.

Another limitation is, although an estimated attrition of 10.0% was calculated, the estimated sample size of 125 could not be reached due to 29 lost data points. The reasons for lost data points included death, referral to the district hospitals, and unknown reasons. However, the lost data points may not have had a serious influence on the results. The results of this study were similar to those of other studies, namely, that the stroke patient's care dependency decreased from the time of the hospital stay up until the 13th week of follow-up.

## Conclusions

The findings from this research indicate that there is a change in the degree of care dependency from the time of hospital admission up until the 13th week visit to the outpatient unit. During the first and second week of stroke care, nurses have many opportunities to support and encourage the patient's independence through standardized nursing care. During the follow-up care period, an essential program to improve family participation and offer community nursing care is needed. This can be important in decreasing care dependency in stroke patients in terms of their mobility. Hospital-based and community-based services should include continual care dependency monitoring using this comprehensive instrument. Care dependency changes over time, and measurements provide the evidence needed to plan for improvements in stroke care and continual community programs.

## Conflicts of interest

The authors have no conflicts of interest to declare.

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