Relationship Between Awareness of Disability and Occupational Performance During the First Year After a Stroke

Lisa Ekstam, Brittmari Uppgard, Anders Kottorp, Kerstin Tham

KEY WORDS
• disability
• geriatric
• occupational performance
• stroke

OBJECTIVES. This study examined the relationship between awareness of disability and occupational performance in a group of elderly persons during the year after stroke.

METHOD. Data on awareness of disability and occupational performance (i.e., activities of daily living [ADL] motor and process ability) were collected 1, 3, 6, and 12 months after stroke. A mixed-linear-effects model was implemented to examine the relationship between awareness of disability and ADL motor and process ability over time.

RESULTS. Increased awareness of disability was related to improvements in occupational performance (ADL motor and process ability). The 2 relationships were different, with a positive linear relationship between awareness of disability and ADL motor ability, and a stronger, positive, nonlinear relationship between awareness of disability and ADL process ability.

CONCLUSION. Clients’ awareness of disability and their ability to perform occupations should be assessed several times during a rehabilitation process so that interventions can be adjusted to match each client’s potential to benefit from them.


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Lack of awareness of disability is common after a stroke (Hartman-Maeir, Soroker, Oman, & Katz, 2003; Prigatano & Schacter, 1991), a pattern that previous studies have indicated has a negative effect on occupational performance and the outcome of rehabilitation. For example, a lack of awareness of disability after acquired brain injury has been found to influence a person’s motivation to engage in rehabilitation (Fleming, Strong, & Ashton, 1998; Katz & Hartman-Maeir, 2004; Tham & Borell, 1996) and also may interfere with efficient, safe, and independent functioning in everyday life (Hartman-Maeir et al., 2003; Hartman-Maeir, Soroker, Ring, & Katz, 2002; Tham, Ginsburg, Fisher, & Tegner, 2001). There is a risk that people who lack an awareness of disability have a decreased judgment of what they can accomplish safely and thus may insist on participating in occupations beyond their capacity—for example, continuing to live independently at home without support or driving a car (McGlynn & Schacter, 1989; Toglia & Kirk, 2000), which can be dangerous for themselves and to others. The previously mentioned studies suggest that awareness of disability influences occupational performance, but no study has specifically evaluated how the relationship between awareness of disability and occupational performance evolves over time.

Occupational performance in this study is defined as “a meaningful sequence of actions in which the person enacts and completes a specified task that is relevant to his or her culture and daily life roles” (Fisher, 2003, p. 24). A commonly used definition of awareness is “the capacity to perceive the ‘self’ in relatively ‘objective’ terms while maintaining a sense of subjectivity” (Prigatano & Schacter, 1991,
The present study focuses on awareness of the person’s limitations in occupational performance, and the concept of awareness of disability is operationally defined as “no discrepancy between a person’s observed task limitations and the experienced and self-described task limitations after the performance of specific ADL [activities of daily living] tasks” (Kottorp & Tham, 2005, p. 9).

Some aspects that influence people’s awareness of disability have been described in reports on empirical research. Previous studies have shown that feedback from others (Tham & Kielhofner, 2003), video feedback (Tham & Tegner, 1997), and a person’s reflective use of experiences of successes or failures during the performance of occupations can influence the awareness of disability of persons who have had a stroke. How people gradually become aware of their abilities and disabilities after stroke through the experience of performing everyday occupations also has been described (Levine, 1990; Tham, Borell, & Gustavsson, 2000). More than any other environment, being at home encourages people to assume meaningful activities and also empowers them to assume responsibility for their own rehabilitation process (von Koch, Holmqvist, Wottrich, Tham, & de Pedro-Cuesta, 2000). Increasing people’s awareness of disability seems to enable them to adapt the way they perform occupations consciously, to use compensatory strategies (Crosson et al., 1989) and, gradually, to incorporate conscious strategies as they develop new habits (Erikson, 2005; Tham et al., 2000).

Research that systematically examines the relationship between awareness of disability and occupational performance over time is needed to determine when and how to implement intervention strategies aiming to improve awareness of disability and occupational performance. This study, therefore, sought to examine the relationship between awareness of disability and occupational performance in a group of elderly persons during the year after they had a stroke. The specific questions addressed were (a) Are there changes in awareness of disability and occupational performance in the group in the year subsequent to a stroke? (b) What characterizes the relationships between awareness and occupational performance? (c) Does the time that has elapsed since the stroke influence the relationship between the participants’ awareness and their occupational performance?

Methods

Design

The study was a longitudinal prospective study of 34 elderly persons participating in rehabilitation at home after stroke. Measures of awareness of disability and occupational performance were conducted 1, 3, 6, and 12 months after the stroke. The study was approved by the Karolinska Institute, Stockholm, Sweden.

Participants

During the 10 months of inclusion of study participants, 114 patients at a geriatric clinic in Stockholm, Sweden, were assessed for their eligibility to participate in the study. The criteria for participation in the study were that (a) patients should participate in the home rehabilitation program, (b) less than 1 month had passed since their stroke, (c) they were able to understand instructions and questions (as verified by the occupational therapist or research assistant’s evaluation), and (d) they had not been diagnosed with dementia. Thirty-five patients were judged by the stroke team to have both a need for and enough functional ability to participate in the home rehabilitation program. The stroke team’s criteria were that the patients should be able to take an active part in home rehabilitation interventions and to transfer to the toilet with or without aid. If they were living alone, participants had to be able to be alone at home for some hours per day and during the night, to use the alarm connected to a home help service, and to open the front door.

After agreeing to participate in the home rehabilitation program, the 35 patients received written and verbal information about the study from a research assistant (the second author). One patient did not fulfill the criteria for participation in the study, because of aphasia, but the other 34 patients (from now on referred to as participants) fulfilled the inclusion criteria for participating in the home rehabilitation and agreed in oral consent to participate in the study.

The baseline demographics and clinical characteristics of the 34 participants are presented in Table 1 to give an overview of the study group. When examining awareness of disability and occupational performance in the year after a stroke, we found that complete data were collected for 26 participants 1, 3, 6, and 12 months after stroke, and 8 participants were missing one or more of the interview sessions. A comparison between the 26 participants who completed the sessions and the 8 dropouts revealed that the latter had a slightly older median age (79 vs. 84 years, which was a significant difference), but no significant differences were found in relation to their gender and hemisphere lesions.

Study Context

In the acute stage, the participants received care at an acute stroke unit for an average of 5.8 days (range = 2–12),
Table 1. Demographic Data for and Clinical Characteristics of Participants, Collected 3–12 Days After Stroke

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sample at First Assessment (N = 34)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age (IQR)</td>
<td>81.5 (75–84)</td>
</tr>
<tr>
<td>Men</td>
<td>9</td>
</tr>
<tr>
<td>Women</td>
<td>25</td>
</tr>
<tr>
<td>Scandinavian Stroke Scale, median (range)*</td>
<td>49 (24–58)</td>
</tr>
<tr>
<td>Living with someone</td>
<td>10</td>
</tr>
<tr>
<td>Living alone</td>
<td>24</td>
</tr>
<tr>
<td>Housing, apartment</td>
<td>34</td>
</tr>
<tr>
<td>Housing, service apartment</td>
<td>0</td>
</tr>
<tr>
<td>Country of origin</td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td>31</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>Previous stroke</td>
<td>15</td>
</tr>
<tr>
<td>No previous stroke</td>
<td>19</td>
</tr>
<tr>
<td>Hemisphere lesion</td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>16</td>
</tr>
<tr>
<td>Left</td>
<td>16</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>Katz extended before stroke, median (range)**</td>
<td>20 (12–20)</td>
</tr>
<tr>
<td>Dysphasia</td>
<td>6 (n = 33)</td>
</tr>
<tr>
<td>No dysphasia</td>
<td>27</td>
</tr>
<tr>
<td>MMSE, median (range)***</td>
<td>27 (19–29)(n = 25)</td>
</tr>
</tbody>
</table>

*Scandinavian Stroke Scale (Scandinavian Stroke Study Group, 1985) (max score 58); **Katz extended (Hulter-Åsberg & Sonn, 1988) (max score 20); ***MMSE = Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) (max score 30).

whereupon they were transferred to a geriatric stroke unit for rehabilitation. At the rehabilitation unit they received occupational therapy and physiotherapy daily for approximately 1–2.5 total hr per day. The intervention was individualized, and the participants also received rehabilitation from the physician, social worker, speech therapist, and psychologist if needed. After being discharged to their homes, after 27.6 (m) days (range = 7–59) at the geriatric stroke unit, the rehabilitation continued in the participant’s home, with the rehabilitation provided by the same team members as at the geriatric stroke unit.

Three to six times a week, a nurse, an occupational therapist, or the physiotherapist visited the participants in their homes. The other members made home visits when the participant needed their services. The mean duration of the rehabilitation provided at home was 29 days (range = 16–68 days), with an average of 18.6 home visits being made by the rehabilitation professionals (range = 4–54 visits), and the mean time spent per home visit was 57 min. The program was based on principles for client-centered practice (Law, Baptiste, & Mills, 1995), and the interventions were task-oriented (meaning that they were individually purposeful and meaningful) and performed in the client’s home or in the community. During the current study, no follow-up interventions were done after discharge from the home rehabilitation program.

Data Collection

A research assistant (the second author, an experienced occupational therapist) recruited the participants to this study and collected all data. Data collection started when the participants were still inpatients at the stroke unit, and the first assessments were conducted at the hospital 1 month after the stroke. After 3, 6, and 12 months had elapsed since the stroke, data were collected in the participants’ homes. To measure occupational performance in self-chosen and client-relevant ADL tasks, the Assessment of Motor and Process Skills (AMPS; Fisher, 1999) was used. Awareness of disability was evaluated using the Assessment of Awareness of Disability (AAD), originally developed by Tham, Bernspang, and Fisher (1999) and further refined by Kottorp and Tham (2005).

Instrumentation

The AMPS (Fisher, 2003) is a client-centered, performance-based assessment of both the ability to perform personal or instrumental ADL tasks (ADL–ability) and the discrete motor and process skills necessary for efficient and effective task performance (American Occupational Therapy Association, 2002). Its battery of tasks allows the occupational therapist to evaluate a client’s ADL motor and process skills (on the AMPS motor and process scales) using tasks that are familiar, contextually relevant, and chosen by the client (Fisher, 2003).

Based on a structured interview, the occupational therapist selects various ADL tasks from the battery of 83 tasks, from which the client will choose 2 tasks and will perform them. This process is described in greater detail in the manual (Fisher, 2003). The ADL motor skills are defined as the observable goal-directed actions that a person uses during the performance of ADL tasks to move himself or herself or the objects required to accomplish the task (Fisher, 2003). ADL process skills are the observable goal-directed actions involved in performance that reflect a person’s ability to logically sequence the actions required to perform ADL tasks over time, select and use appropriate tools and materials, and effectively adapt his or her performance (Fisher, 2003).

Each of the 20 ADL motor skill items and 20 ADL process skill items were scored on the basis of the quality of performance, where 4 = competent, 3 = questionable, 2 = ineffective, and 1 = deficient. A Rasch-based AMPS computerized scoring program (Computer Adaptive Technologies & Fisher, 1994–1996) was used to convert the raw scores into two linear measures of ADL ability—ADL motor ability and ADL process ability—adjusting for task challenge, rater severity, and item difficulty. This process has been further described elsewhere (Fisher, 1993, 1999).
On the ADL motor scale, persons with ability measures below 2.0 logits are likely to need to expend a considerable amount of effort to accomplish an ADL task, and a value of less than 1.0 logits on the ADL process scale indicates a need for assistance if a person is to live in the community (Fisher, 2003). The AMPS has been examined and used as a valid measure of ADL ability (i.e., both ADL motor and ADL process ability) in a considerable number of investigations on clients who have had a stroke (Bernspång & Fisher, 1995a; Rexroth, Fisher, Merritt, & Gliner, 2005; Wittenberg et al., 2003).

The AAD evaluation is based on a semistructured interview, which is used in conjunction with the AMPS. The AAD measures a person’s awareness of his or her disability by assessing the discrepancy between the observed level of skill and that experienced and reported by the person for a specific ADL task (Kottorp & Tham, 2005; Tham et al., 1999). The AAD has demonstrated a desired level of stability over time (test–retest reliability; Hallgren & Kottorp, 2005; Kottorp, Hallgren, Bernspang, & Fisher, 2003; Tham et al., 2001), acceptable internal scale validity, and acceptable person response validity (Tham et al., 1999). The AAD measures also have demonstrated sensitivity to change due to intervention (Hallgren & Kottorp, 2005; Kottorp, Hallgren, Bernspang, & Fisher, 2003; Tham et al., 2001). Finally, rater severity calibrations obtained for different therapists demonstrated consistency across tasks and clients, providing evidence of intrarater reliability (Kottorp & Tham, 2005). The version of the AAD used in this research study consisted of 12 questions related to the performance of ADL tasks, which were posed in an interview conducted immediately after an ADL task had been completed. The therapist evaluated a person’s awareness of disability by assessing the discrepancy between the observed level of skill and the level experienced and reported by the person for a specific ADL task on a scale from 1 (major discrepancy) to 4 (no discrepancy). The individual linear measures of awareness of disability were generated using a computer application of a many-faceted Rasch analysis, Facets (Linacre, 1987–2003). The application of this analysis in the development of the AMPS and the AAD has been described elsewhere (Bernspång & Fisher, 1995b; Kottorp, Bernspang, & Fisher, 2003; Tham et al., 1999).

Data Analysis

Friedman’s test was used to identify any changes in the clients’ awareness of their disability and in their ability to perform ADL during the year. A p value of < .05 was considered to be statistically significant.

A mixed-linear-effect model (Fitzmaurice, Laird, & Ware, 2004) was implemented to describe the time dependence of the influence of awareness of disability on ADL motor ability and ADL process ability over time. This model takes into account any covariance between repeated measures obtained from the same subject. It also takes into consideration all data that include situations in which there are different numbers of repeated measurements or different intervals for different cases or both. Time was viewed as a continuous variable. The model displays the measures for the distribution of awareness of disability, ADL motor ability, and ADL process ability over time.

The variable AD (awareness of disability) was fitted with lower order polynomials, and tests were performed to determine whether awareness of disability related differently to ADL motor ability and ADL process ability over time.

We used AICc (Akaike’s [1974] information criteria corrected) to evaluate which of the potential models was best suited to describe the relationships among awareness of disability and both ADL motor and ADL process ability. A heterogeneous compound symmetry structure gave the most accurate description of the relation between awareness of disability and ADL motor ability over time. This structure assumed that the variances of the times at which the interviews were conducted were heterogeneous but that the covariance between pairs of time points was the same. For the analysis of ADL process ability, a Toeplitz covariance structure was found to be the most appropriate (Weiss, 2005). In this model, the variance was assumed to be equal at each point in time (Weiss, 2005).

Cook’s distance and scatter plots of the predicted values versus the raw residuals were used to detect outliers. The analyses were performed using SAS software, version 9.1.3, and the procedure, Mixed.

Results

Over the year of the study, the participants’ awareness of disability (p < .01), ADL motor ability (p < .01), and ADL process ability (p < .01) improved. At 12 months after stroke, the median for the ADL motor ability (0.25 logits) was still lower than the level at which people are likely to be able to perform ADL tasks without increased effort. The median value obtained for the process ability associated with ADL 12 months after the time of the stroke (0.8 logits) was close to, but still lower than, the level at which a person was likely to be able to perform the tasks involved in ADL efficiently, safely, and independently.

The participants’ ADL motor ability improved as their awareness of disability increased, but this relationship was not uniform over time (see Table 2). A significant positive relationship between awareness of disability and ADL process ability also was found during the year (p < .01),
although it was neither linear nor consistent over the time that had elapsed since the stroke ($p < .01$; see Table 2).

The slopes of the regression model describing the relationships between awareness of disability and ADL motor ability (see Figure 1) were significantly different between the periods 1–6 months ($p < .01$), 1–12 months ($p < .01$), and 3–12 months ($p < .03$), indicating that the relationship between awareness of disability and ADL motor ability became stronger over time. Figure 1 also shows the progression of awareness of disability and ADL motor ability over the four periods of study. The regression model describing the relationships between the awareness of disability and ADL process ability (see Figure 2) was significantly different at 12 months compared to the models obtained for earlier times for which measurements were available, 1–12 months ($p < .01$), 3–12 months ($p < .05$), and 6–12 months ($p < .05$). This result indicates not only that the relationship between awareness and ADL process ability changed in relation to time but also that changes in awareness were related to more or fewer changes in ADL process ability, due to levels of awareness; that is, in the early phases after stroke (3 months), participants with a higher level of awareness demonstrated a much stronger relationship to ADL process ability than did those with a lower level of awareness. After 12 months, an opposite pattern was revealed: Participants with a lower level of awareness demonstrated a much stronger relationship to ADL process ability than did persons with a higher level of awareness. Figure 1 also shows the progression of awareness of disability and ADL process ability over the four periods of study.

**Discussion**

The participants’ awareness of disability and their occupational performance (i.e., ADL motor and process ability) improved during the year after their stroke. However, this

<table>
<thead>
<tr>
<th>Effect</th>
<th>Relationship Between Awareness of Disability and ADL Motor Ability (P value)</th>
<th>Relationship Between Awareness of Disability and ADL Process Ability (P value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>.099</td>
<td>.2317</td>
</tr>
<tr>
<td>AAD</td>
<td>&lt; .001</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>AAD by time</td>
<td>.043</td>
<td>.0105</td>
</tr>
<tr>
<td>(AAD)$^2$</td>
<td>—</td>
<td>.8585</td>
</tr>
<tr>
<td>(AAD)$^2$ by time</td>
<td>—</td>
<td>.0034</td>
</tr>
</tbody>
</table>

Note. ADL = activities of daily living; AAD = Assessment of Awareness of Disability (Tham, Bernspang, & Fisher, 1999).

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Figure 1. Scatter plots for each occasion on which the participants were assessed 1, 3, 6, and 12 months after stroke, showing the regression line and confidence interval of the relationship between awareness of disability and ADL motor ability.
group of elderly persons living at home after having had a stroke still had low scores on the AMPS at the end of the year, indicating that living in the community without assistance would have been difficult for them (Fisher, 2003). The analysis of the data (using the mixed-linear-effect model) identified that the increased awareness of disability was related to improvements in occupational performance. Awareness of disability and ADL motor ability, as well as awareness of disability and ADL process ability were positively correlated. The two relationships were somewhat different, however, demonstrating a linear positive relationship between awareness of disability and ADL motor ability and a more complex, stronger, and nonlinear positive relationship between awareness of disability and ADL process ability.

These results have some important clinical implications. The first clinical implication is that clients’ awareness of disability and their ability to perform occupations should be assessed several times during a rehabilitation process (i.e., process of change) so interventions can be adjusted to match each client’s potential to benefit from them. When a client’s ADL ability is low and he or she shows a lack of awareness of disability, it may indicate that the intervention strategies should concentrate on factors other than the client, such as introducing environmental modifications or instructing caregivers on how to support occupational performance (Fisher, 2003). A previous qualitative study that examined the process involved when persons with stroke and unilateral neglect became increasingly aware of their disability (Tham et al., 2000) indicated that the nature of the relationship between awareness of disability and a participant’s ability to perform occupations changed during the different phases of the process, which had implications for the planning of interventions. At an early stage in the recovery after a stroke, the participants involved in the studies conducted by Tham and colleagues (2000, 2003) revealed that the participants were less aware of their disability than they would be at a later stage and needed more support and guidance to attain important experiences of occupational performance. During this stage, a lack of awareness can, for example, result in performing activities beyond one’s actual ability, with negative consequences (including injury) (McGlynn & Schacter, 1989).

The second major clinical implication is that awareness of disability may be more strongly related to ADL motor ability in the later phases of the first year after a stroke than in the first few months, which may indicate that more concern should be taken to increase awareness of disability in the later phases to maximize the improvement in ADL.
motor ability. The time elapsed since the stroke occurred has not been systematically evaluated as a confounder in earlier studies evaluating relationships between cognitive function and occupational performance in clients with stroke (Kizony & Katz, 2002; Mercier, Audet, Hebert, Rochette, & Dubois, 2001). Thus, studies with a cross-sectional design, which do not consider the time elapsed since the stroke, might overestimate or underestimate the relationship between awareness of disability and occupational performance.

Because the relationship between awareness of disability and ADL motor ability was weaker than the relationship between awareness of disability and ADL process ability—which is in line with other studies (Kizony & Katz, 2002)—a third implication might be that it is clinically important to be aware of the positive relationship between awareness of disability and ADL motor ability when conducting the AMPS. The scores the researchers assign to the ADL motor skills represent a judgment of how competent, or skilled, a person is at performing motor actions within a relevant context when conducting a meaningful and purposeful task. It could, therefore, be assumed that even though a person’s underlying motor impairments are not directly influenced by his or her awareness of disability, an increased awareness of disability might provide the person with a longer term means of compensating for the motor impairments by using technical aids or different compensatory strategies and, in so doing, improve his or her ADL motor skills.

Limitations

Because the number of participants was limited, the results cannot be generalized. To be generalized, the result needs to be confirmed in larger studies using a more varied sample.

Age has been shown to have an impact on both ADL motor and process ability measures (Hayase et al., 2004). Because the sample of this study was composed solely of persons older than 65 years, their age could have had an impact on the ceiling effect found in ADL process ability in relation to awareness of disability at the 12-month follow-up. However, as long as these results are used only for comparisons within the same age group, this factor should not be a serious concern, especially because stroke is most common among elderly persons.

The AAD is an instrument under development, which may have influenced the reliability and validity when measuring awareness of disability. However, previous studies have revealed the AAD to be valid and reliable, as well as sensitive to changes arising from interventions (Hällgren & Kottorp, 2005; Kottorp, Bernspang, & Fisher, 2003; Tham et al., 1999, 2001). Advantages of the AAD and the AMPS are that they are both occupation-based, client-centered, and top-down assessments, whereas AAD measures the discrepancy between the individuals’ observed ADL limitations and their perceived and self-described ADL limitations after the performance of a specific client-relevant and self-chosen ADL task. In adopting this approach, the AAD fulfills the criteria laid down by Simmond and Fleming (2003), who stated that the phenomenon of awareness of disability is best captured in an assessment that combines observations of occupational performance and well-timed questions.

Future Studies

In this study we considered the natural course of the relationship between awareness of disability and occupational performance in a group of elderly persons participating in a home rehabilitation program, during the first year after they had had a stroke. It would be valuable to identify improvements and relationships between awareness of disability and occupational performance after a stroke, for example, by conducting a randomized controlled trial to systematically evaluate occupation-based, client-centered occupational therapy interventions, including follow-ups 3 months after stroke (which was not done in this study).

Future studies preferably would use the mixed-linear-effect model, which can specify the relationship between the awareness of disability and ADL process ability and between the awareness of disability and ADL motor ability, both of which have been found to be complex and complicated, in addition to which they appear to be influenced by other factors (e.g., time). A longitudinal design in combination with the mixed-linear-effect model may be the most suitable method with which to clarify such relationships.

Evidence that the regression line flattens out at 12 months could be attributable to the low number of participants, because isolated values have greater weight in a smaller data set in the estimation of a regression line. The increasing confidence intervals in the endpoints of the regression line may, to some extent, compensate for such a displacement. Another plausible explanation for the curve might be that there is a ceiling in the ADL process ability at 12 months, indicating that the vast majority of the improvement that will be made in this respect has been made by this time. Despite a high awareness of disability, several other factors can have an impact on the measures of ADL process ability. One could be that, at 12 months, the participants still experienced ADL motor difficulties that affected their ability to perform ADL tasks efficiently, safely, and independently. Previous research (Fisher, 2003) also has
indicated that low ADL motor ability measures increase the demand on ADL process skills. In this study, because of the limited number of participants \( (n = 34) \), no attempt was made to develop a regression model that focused on how ADL motor ability and awareness of disability may interact and influence ADL process ability over time. However, it would be interesting to identify whether any such interaction exists between these variables in a larger sample. ▲

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