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Elderly Patients' Knowledge of Drug Benefit Caps and Communication with Providers About Exceeding Caps

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OBJECTIVES: Many elderly persons have drug benefits with coverage gaps, such as in Medicare Part D. Because beneficiaries who have such gaps must pay all drug costs, an accurate knowledge of gap thresholds and communication with providers about exceeding caps is important for elderly persons to manage out-of-pocket drug costs.

DESIGN: Cross-sectional survey.

SETTING: Health plan.

PARTICIPANTS: One thousand three hundred eight health plan members aged 65 and older. The study was a 2002 cross-sectional survey of elderly persons with capped drug benefits in a managed care plan in one state. Participants were sampled so that half reached coverage caps and half did not.

METHODS: Participants reported cap levels, communication with providers about exceeding caps, and decreased medication use due to cost.

RESULTS: Of the 1,308 participants (65.4% response rate), 68.6% did not know their correct cap level. Rates were similar in those who exceeded caps (66.2%), reported difficulty paying for medications (63.9%), or decreased medication use (66%). For participants who exceeded caps, 59.1% did not know beforehand that they were close to exceeding caps and 50.2% did not tell providers afterward. In multivariate analyses accounting for demographics and health, the oldest participants (≥ 85 vs 65–74) were at greater risk for not knowing cap levels (odds ratio (OR) = 2.0, 95% confidence interval (CI) = 1.2–3.4) and not telling providers about exceeding caps (OR = 2.2, 95% CI = 1.1–4.5).

CONCLUSIONS: Elderly patients often did not know correct cap levels and did not tell providers about exceeding caps. Providers, plans, and policymakers should actively assess and improve Medicare beneficiaries' knowledge of Part D coverage gaps. *J Am Geriatr Soc* 57:848–854, 2009.

Key words: Medicare Part D; medication costs; drug benefit design; patient communication

Of the approximately 24 million beneficiaries enrolled in Medicare Part D in 2007, 3.4 million reached the “coverage gap”: between \$2,400 and \$5,451 in total drug expenditures, where beneficiaries pay 100% of drug costs out of pocket.^{1,2} This represented 26% of the Part D enrollees who filled at least one prescription in 2007 but did not receive low-income subsidies.² Thus, understanding whether elderly patients correctly know the dollar threshold of coverage gaps is important.³ Patients who do not know their coverage gap or are mistaken about the gap threshold can be caught unaware when they exhaust their coverage. This loss of drug coverage, albeit temporary, has strong clinical implications, because it places elderly patients at greater risk for decreasing use of important medications because of cost.^{3–11} Gaps in knowledge about drug benefit design has been associated with patients being more likely to report being nonadherent with medications because of cost and to experience financial difficulty paying for medications.^{3,11}

Significant concerns have been expressed about the complexity of Part D and whether it poses a barrier to beneficiaries' ability to navigate their drug benefits.^{12,13} Because Part D is so new, most studies have concentrated on beneficiaries' knowledge of Part D with respect to their decision about whether to enroll (e.g., the penalty for late enrollment, qualifying for low-income assistance, source of information about Part D).^{12,13} Few studies have addressed beneficiaries' knowledge of the Part D coverage gap.^{3,13} A

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recent study of Part D enrollees in Kaiser Permanente Northern California found that 60% of participants were unaware of the coverage gap in their drug benefit.³ Even of those who reached the coverage gap, 11% to 25% remained unaware of the gap. However, studies have yet to report which beneficiaries are the most vulnerable and how age, education level, race or ethnicity, and income affect patients' risk for poor knowledge of such benefit thresholds. Additionally, whether beneficiaries tell their providers about exceeding coverage gaps is also unknown. This is also important, because communication between patients and doctors about drug costs occurs infrequently.^{14–17}

This study examined how well elderly patients before Part D knew the caps on their drug benefits. Before Part D, some 4.5 million Medicare beneficiaries were enrolled in managed care plans, the vast majority of which had coverage gaps in the form of capped drug benefits.¹⁸ These caps were similar to the Part D coverage gap in that members who exceeded caps paid 100% of drug costs until their benefits restarted the following year. The data came from a survey of Medicare beneficiaries with capped drug benefits, half of whom exceeded their caps. Beneficiaries were asked about their cap levels, communication with providers about exceeding caps, difficulty paying for medications, and decreasing medication use due to cost. The relationship between not knowing cap levels and difficulty paying for medications and decreased medication use due to cost was also examined. Using this information, health plans and policymakers can gauge the necessity of evaluating Medicare beneficiaries' current knowledge of the Part D coverage gap and implement changes in how such information is communicated.

Setting and Study Design

Data came from a cross-sectional survey of 1,308 members aged 65 and older in a single health plan with more than 400,000 members in one state.⁵ Members had \$750 to \$2,000 annual caps on the plan's share of prescription costs (i.e., the plan paid for prescription costs (drug cost minus a member's copayment) until the sum of these payments reached the cap (e.g., \$750)). Afterward, members paid all drug costs out of pocket for the rest of the year. Prescription copayments ranged from \$7 to \$30 per 30-day prescription. There were no deductibles, and all beneficiaries had the same drug formulary. The participating plan provided information to members about their cap levels in their annual membership benefits report. Throughout the year, members could call a toll-free help line to find out how close they were to exceeding the cap.

Because the primary goal of the survey was to study the effect of caps on medication use, half of the participants were randomly sampled from members who exceeded \$750 or \$1,200 caps for 75 to 180 days before the end of the year in 2001.⁵ The other half of participants were sampled from members with \$2,000 caps who did not exceed their cap but whose total drug expenditures were similar to those of members who exceeded the lower caps. Additional eligibility requirements included aged 65 and older, not receiving assistance from Medicaid, and ability to complete the survey in English. Members who self-reported as too ill to participate or who were unable to give informed consent were excluded. Participants were surveyed once between

March and July 2002 over the telephone or with a written questionnaire (sent to those who asked for mailed surveys or could not be contacted by telephone).

Measuring Participant Demographics

Participants reported age, sex, education, race, annual income, self-rated health, ability to perform instrumental activities of daily living (IADLs), and 10 common health problems (hypertension, diabetes mellitus, heart disease, depression, stroke, cancer, peptic ulcer disease, hypercholesterolemia, osteoporosis, and bronchitis or asthma). The majority of participants provided actual incomes (47%) or income ranges (40%). The incomes of participants who provided only income ranges or no income information (13%) were imputed using the median income of participants who provided income information and were from the same household size. The 2001 pharmacy data were used to determine who exceeded caps and to calculate average monthly total drug expenditures for participants (sum of drug costs paid by each member and of costs paid by the plan). For those who did not exceed caps, monthly drug expenditures were averaged across all of 2001. For those who exceeded caps, monthly drug expenditures were averaged from the beginning of the year up to the time when they exceeded the cap.

Measuring Knowledge About Caps Levels and Communication

For all participants, the accuracy of their knowledge about cap levels was accessed by asking for the annual dollar maximum on their drug benefit in 2001 and by confirming responses with actual cap levels from membership files. Responses were scored as correct if their stated cap was within 95% to 105% of the dollar amount of their actual cap, incorrect if not, and do not know if they chose this response. Participants who exceeded caps were also asked, "Did you use up the annual maximum on your annual prescription benefit?" (yes/no/do not know), followed by, "Before you ran out of benefits, did you know you were close to using it up?" (yes/no) and "Did you tell your doctor afterwards that you had used up your drug benefit?" (yes/no).

Measuring Decreased Medication Use and Difficulty Paying

To measure decreased medication use, all participants were asked whether they had stopped, used less, or did not start medications because of cost. Participants also reported if they had difficulty paying for their medications. Participants who responded somewhat difficult or very difficult were considered to have given yes responses.

Statistical Analyses

Simple descriptive analyses were used to report how often participants correctly knew cap levels, whether they knew beforehand they were close to exceeding the cap, and whether they told providers about exceeding caps. Multivariate analyses (SAS PROC Logistic) were conducted to examine which participant characteristics were associated with greater likelihood of not knowing the cap (for all participants) and of not communicating with providers about exceeding the cap (for participants who exceeded the cap).

For participants who exceeded the cap, multivariate analyses were also conducted to examine associations between not knowing cap levels and not knowing one was close to exceeding the cap, with difficulty paying for medications and decreased medication use. Based on previous studies of patient characteristics associated with knowledge of Medicare and communication with physicians about cost, age, sex, income, ethnicity, education, income, self-rated health, limitations in IADLs, number of health conditions, having other drug coverage, average total monthly drug expenditures, and whether participants reported income data were included in the model.^{3,11-25}

RESULTS

Beginning with the random sample of 2,344 potentially eligible participants (1,172 study, 1,172 control), 345 (15%) were excluded because of death, self-report of too ill to participate, disenrollment from the participating health plan, or inability to complete the survey in English. Of the remaining 1,999 participants, 1,308 completed surveys (65%), 454 refused (23%), and contact could not be established with 237 (12%). Counting all those who refused or could not be contacted as potentially eligible, this resulted in a Council of American Survey Research Organizations response rate of 67%.

Demographic Characteristics

Participants were on average aged 75.9; 64% were female, 88% were white, 83% had at least a high school degree, 68% had an income of less than \$30,000, and 40% reported fair or poor health (Table 1). Average monthly total drug expenditures for participants was \$208 (5th–95th percentile: \$139–281). Two-thirds had total drug expenditures greater than \$2,250, the coverage gap threshold when Medicare Part D started in 2006. Eighty-six percent said they were the primary person responsible for filling their prescriptions, and the remainder considered a spouse or family member to be the primary person. Age and sex were available for nonrespondents, who were slightly older than respondents (77.1 vs 75.9, $P < .001$) but similar in sex distribution.

Difficulty Paying for Medications and Decreased Medication Use

Fifty percent of participants said it was difficult to pay for medications, and 20% decreased medication use because of cost (Table 1).

Correct Knowledge of Cap Levels and Exceeding the Cap

Sixty-eight percent of participants did not know their cap level (56.4%) or gave an incorrect cap level (12.3%) (Table 2). Rates were high even among participants who had decreased medication use (66.2%), had difficulty paying for medications (63.9%), or exceeded caps (66.3%). Of the participants who said they knew their cap but gave an incorrect cap level, nearly 95% were inaccurate by more than \$150, or 15% of their cap level. Two-thirds overestimated their cap on average by an additional 100% of their actual cap or \$856 (5th percentile \$250, 95th percentile \$1,750). One-third of those who gave incorrect cap levels underestimated their

Table 1. Participant Characteristics

Characteristic	All (n = 1,308)	Did Not Exceed Cap (n = 643)	Exceeded Cap (n = 665)
Age (average)	75.9 years	75.7 years	76.1 years
65–74	43.9%	44.6%	43.2%
75–84	47.4%	46.7%	48.1%
85 and higher	8.7%	8.7%	8.7%
Female	63.8%	68.3%	59.4%
White	88.3%	89.0%	87.7%
Education*			
Less than high school	17.0%	15.7%	18.2%
High school	34.3%	33.7%	34.8%
Some college	30.2%	30.9%	29.5%
College or higher	18.6%	19.7%	17.5%
Annual income (average)	\$31,322	\$29,800	\$32,794
≤\$30,000	68.4%	71.1%	65.9%
\$30,001–50,000	16.1%	14.1%	17.9%
\$50,001 and higher	15.5%	14.8%	16.2%
Has other insurance that pays for drugs	8.1%	7.9%	8.2%
Health status*			
Excellent	5.2%	4.8%	5.6%
Very good	18.4%	18.1%	18.7%
Good	35.9%	38.4%	33.4%
Fair	29.3%	28.1%	30.5%
Poor	11.2%	10.6%	11.7%
Instrumental activities in daily living (IADLs)			
1 or more limitations	32.7%	33.1%	32.3%
No. of health conditions out of 10 measured			
0–5 conditions	89.6%	88.4%	90.7%
≥6 conditions	10.4%	11.6%	9.3%
Average monthly total drug expenditures*	\$208 (std dev \$44)	\$207 (std dev \$44)	\$209 (std dev \$45)
\$0–150	9.7%	9.9%	9.5%
\$151–250	74.2%	74.2%	74.1%
≥\$251	16.1%	15.9%	16.4%
Gave income information	87.5%	85.5%	89.3%
Telephone survey (vs written)	67.8%	63.6%	71.9%
Had difficulty paying for medications	49.9%	36.6%	62.8%
Decreased medication use due to cost	20.3%	16.5%	24.0%

*Percentages do not always add to 100% due to rounding error.

caps, on average by 31% of their actual cap or \$531 (5th percentile \$62, 95th percentile \$1,090). Of participants who exceeded caps, 90.7% knew they had done so, but 59.1% did not know beforehand they were close to exceeding the cap (Table 2). In multivariate analyses adjusting for demographics, health, and exceeding the cap, participants aged 85 and older (odds ratio (OR) = 2.0, 95% confidence interval (CI) = 1.2–3.4) and those who gave no income information (OR = 2.5, 95% CI = 1.7–5.0) were the least likely to know the correct cap level (Table 3). There were no significant predictors associated with not knowing beforehand about exceeding caps.

Table 2. Knowledge of Cap Levels and Communication with Providers

Knowledge and Communication	%*			
	All Participants (N = 1,308)	Decreased Medication Use (n = 263)	Difficulty Paying for Medications (n = 649)	Exceeded Cap (n = 662)
Knowledge of cap level				
Gave correct cap	31.4	33.8	36.1	33.7
Did not know correct cap	68.6	66.2	63.9	66.3
Gave incorrect cap	12.3	14.8	12.5	18.7
Did not know	56.4	51.3	51.5	47.7
Knowledge of exceeding cap				
Did not know exceeded cap	NA	NA	NA	9.3
Did not know beforehand close to exceeding cap	NA	NA	NA	59.1
Communication				
Did not tell provider about exceeding cap	NA	NA	NA	50.2

*Percentages do not add to 100% because of rounding.

NA = not available.

Communication with Providers About Exceeding the Gap

Fifty percent of participants who exceeded caps did not tell their providers (Table 2). In multivariate analyses, patients aged 75 to 84 (OR = 2.2, 95% CI = 1.5–3.1) and aged 85 and older (OR = 2.2, 95% CI = 1.1–4.5), as well as participants who gave no income information (OR = 2.0, 95% CI = 1.2–5.0) were the least likely to have told providers about exceeding the cap (Table 3).

Association Between Cap Knowledge and Difficulty Paying and Medication Use

In multivariate analyses of participants who exceeded caps, those who did not know the correct cap level were less likely to have reported difficulty paying for medications. There was no significant association between not knowing the correct cap and decreasing medication use due to cost. There were no significant associations between not knowing beforehand about exceeding the cap and risk for difficulty paying for medications and risk for decreasing medication use due to cost (Table 4).

DISCUSSION

In this study, two in three elderly patients did not know the correct cap level on their drug benefits even if they exceeded the cap, experienced difficulty paying for medications, or decreased medication use because of cost. These results confirm previous study findings that 60% of Kaiser Northern California Part D enrollees were unaware of their coverage gaps³ and (also before Part D) that 41% of patients aged 50 and older could not say whether their drug coverage had annual limits.¹¹ This suggests the need for providers, health plans, and the Centers for Medicare and Medicaid Services (CMS) to improve communication with patients and physicians about Part D program benefit structure and the risk of reaching the coverage gap.

The current study found that six in 10 participants who exceeded caps were unaware beforehand that they were close to doing so. CMS requires health plans to inform members about total drug expenditures to date but not whether they are likely to reach the coverage gap before the end of the year. Given the dramatic effect of the loss of

coverage on increasing financial burden and decreasing medication use, health plans could monitor drug expenditures for patients early in the year (e.g., the first quarter) and inform patients and their physicians of the patients' likelihood of reaching the coverage gap before the end of the year if their drug costs continue at the same rate. Health plans could also inform patients in which month they are likely to reach the coverage gap, which of their medications contribute the most to their reaching the coverage gap, how much their out-of-pocket drug costs could increase once they do so, and any potentially cheaper appropriate drug substitutions. Such information would help patients discuss with their providers ahead of time whether there are any less expensive but potentially effective medication options that could reduce their risk of reaching the gap.

Additionally, because 12% of the participants thought they knew their benefit cap but gave a dollar amount that was not correct (on average, off by more than \$740), a review of how such information (coverage gap, total drug expenditures, likelihood of reaching the coverage gap) is presented to and understood by Medicare beneficiaries is clearly important. CMS could consider standardization of such reports from health plans for easier comprehension by patients and providers alike. Health plans could also assist patients (and providers) in knowing cost-sharing information by printing on each member's insurance card his or her coverage gap threshold, any coverage during the gap (e.g., generic-only coverage), and the standard copayments for generic or brand-name drugs.

Of the participants, older age was associated with lower likelihood of knowing the correct cap level. This probably reflects the worse state of physical health (eyesight, hearing, illness), level of cognitive impairment, and level of functional health literacy in the oldest beneficiaries.^{11,19–23} Some of these issues can be addressed using tactics such as appropriate formatting,²² but a better alternative might be for all health plans to allow members to designate family or friends to have access to up-to-date information about their Part D drug benefits and medication use to help them manage their drug benefits. In the current study, 14% of participants indicated that a spouse or family

Table 3. Predictors of Benefit Knowledge and Communicating with Providers About Exceeding Benefit Caps

Participant Characteristic	Adjusted Odds Ratio (95% Confidence Interval)		
	Did Not Know Correct Benefit Cap	Did Not Know Beforehand Close to Exceeding Cap	Did Not Tell Provider About Exceeding Cap
	All (N = 1,270)	Exceeded Cap (n = 578)	Exceeded Cap (n = 564)
Age (reference 65–74)			
75–84	1.2 (0.9–1.5)	0.8 (0.6–1.2)	2.2 (1.5–3.1)*
≥85	2.0 (1.2–3.4)*	0.8 (0.4–1.6)	2.2 (1.1–4.5)*
Female (reference male)	1.2 (0.9–1.6)	1.2 (0.8–1.8)	1.1 (0.8–1.6)
White (reference non-white)	0.9 (0.6–1.3)	0.9 (0.5–1.6)	1.3 (0.7–2.3)
Education (reference ≥college)			
<high school	1.4 (0.9–2.2)	1.3 (0.7–2.5)	0.7 (0.4–1.4)
High school	1.3 (0.9–1.9)	0.8 (0.4–1.3)	0.7 (0.4–1.2)
Some college	1.0 (0.7–1.4)	0.7 (0.4–1.3)	0.8 (0.4–1.3)
Income, \$ (reference ≥\$50,000)			
≤30,000	0.9 (0.6–1.3)	1.1 (0.7–1.9)	1.4 (1.0–1.8)
30,001–50,000	0.9 (0.6–1.4)	0.7 (0.4–1.2)	0.7 (0.4–1.4)
Has other drug insurance (reference no)	0.9 (0.6–1.5)	1.2 (0.7–2.3)	0.8 (0.4–1.5)
Health status (reference excellent)			
Very good	0.7 (0.4–1.3)	1.1 (0.5–2.6)	0.7 (0.3–1.5)
Good	0.8 (0.4–1.4)	1.2 (0.6–2.7)	0.5 (0.3–1.2)
Fair	0.6 (0.3–1.1)	1.1 (0.5–2.6)	0.4 (0.2–1.0)
Poor	0.6 (0.3–1.2)	0.7 (0.3–1.9)	0.6 (0.2–1.7)
≥1 limitations in IADLs (reference no limitations)	1.2 (0.9–1.6)	1.3 (0.8–2.0)	1.1 (0.7–1.6)
≥6 health conditions out of 10 measured (reference 0–5 conditions)	1.0 (0.7–1.5)	1.1 (0.6–1.9)	1.1 (0.6–2.0)
Average monthly total drug expenditures, \$ (reference \$0–150)			
151–250	0.9 (0.6–1.3)	0.8 (0.4–1.5)	1.3 (0.7–2.5)
≥251	1.1 (0.6–1.8)	0.7 (0.3–1.5)	1.1 (0.5–2.3)
Exceeded drug benefit cap (reference no)	0.8 (0.7–1.1)	—	—
Did not give income information (reference gave income)	2.5 (1.7–5.0)*	1.7 (0.9–3.0)	2.0 (1.2–5.0)*
Telephone survey (reference written)	1.0 (0.8–1.4)	1.4 (1.0–2.1)	0.8 (0.5–1.2)

* Statistically significant at $P < .05$.

Adjusted for age, sex, income, ethnicity, education, income, self-rated health, limitations in instrumental activities of daily living (IADLs), number of health conditions, having other drug coverage, average total monthly drug expenditures, and whether participant reported income data.

member was the primary person for filling their prescriptions. Others studies have found that nearly one-third of Medicare beneficiaries rely on others to make their health insurance decisions, including their spouses and children.^{23,24} Interventions to improve knowledge of drug ben-

efits should also use multiple information sources to reach members—elderly persons report using an average of three information sources to learn about Medicare.²¹ Aside from age and not knowing income information, no other demographic characteristics were significantly associated with

Table 4. Association Between Benefit Knowledge and Risk for Difficulty Paying for Medications and for Decreasing Medication Use Due to Cost

Benefit Knowledge	Adjusted Odds Ratio (95% Confidence Interval)			
	All Participants		Participants Who Exceeded Cap	
	Difficulty Paying (n = 1,265)	Decreased Medication Use (n = 1,259)	Difficulty Paying (n = 575)	Decreased Medication Use (n = 574)
Did not know correct cap level	0.6 (0.5–0.8)*	0.9 (0.7–1.3)	0.9 (0.6–1.3)	1.2 (0.8–1.8)
Did not know beforehand close to exceeding cap	—	—	1.1 (0.8–1.7)	1.1 (0.7–1.6)

* Statistically significant at $P < .5$.

Adjusted for age, sex, income, ethnicity, education, income, self-rated health, limitations in instrumental activities of daily living, number of health conditions, having other drug coverage, average total monthly drug expenditures, and whether participant reported income data.

not knowing cap levels, although other studies before Part D indicate that beneficiaries who are nonwhite and have lower income and lower educational levels are less likely to know their copayments, spending limits, enrollment or disenrollment requirements for Medicare, and benefit coverage.^{11,20–22,25}

For participants who exceeded caps, communication with providers about reaching this coverage gap was low (50%). This reflects previous findings that patients and providers often do not discuss drug costs, even though these discussions can help patients.^{14–17} Because many elderly patients prefer to leave the decision-making to their providers,^{26–29} even before patients reach the coverage gap, providers could play an active role by asking Medicare beneficiaries to check how much of their drug benefit remains.

In this study, knowing the correct cap level and knowing beforehand that one was close to exceeding the cap was not associated with a lower risk for experiencing difficulty paying for medications or for decreasing medication use due to cost. This may be because the study did not ask participants when and how they learned about their cap level. Participants could have learned about their cap level only after exceeding it (hence the significant association between those with no difficulty paying for medications also being less likely to know the correct cap level). Because others have found lack of knowledge about drug coverage limits (not necessarily caps) to be associated with decreasing medication use due to cost,¹¹ further studies are needed to explore the relationship between accurate knowledge of drug benefits and medication adherence.³

The limits of this study are that only elderly enrollees from a single health plan in one state before Medicare Part D were included. Thus, the findings do not reflect knowledge of current Medicare beneficiaries about Part D, although given the complexity of Part D and the reported difficulty faced by Medicare beneficiaries in navigating information to enroll, this study highlights the need to improve Medicare beneficiaries' knowledge of drug benefit limits even after enrollment. The study also focused on elderly patients with high drug expenditures, half of whom exceeded caps. Elderly persons with lower drug costs may be in better health or have higher cognitive function, but elderly patients who exceed benefit caps have high policy relevance because they are the most vulnerable to out-of-pocket costs and decreasing medication use due to cost. The study also excluded elderly patients who self-reported being too ill to participate or who were unable to give informed consent, and these patients are likely to have greater gaps in knowledge about their drug benefits. Knowledge can also improve as Medicare beneficiaries gain familiarity with gap thresholds through longer periods of enrollment or reach the coverage gap the previous year (although two-thirds of beneficiaries who exceeded their cap still did not know correct cap levels). Factors such as eyesight, hearing, and health literacy levels that may also affect beneficiaries' knowledge of drug benefits were not measured.

CONCLUSIONS

This study found that elderly patients had poor knowledge of their drug benefit caps and that communication with

providers about exhausting drug coverage often did not occur.

This indicates the need to actively improve Medicare beneficiaries' understanding and knowledge of the Part D coverage gap, as well as their knowledge of their risk for exceeding the gap. Providers should remind patients to check how much benefit they have remaining, and health plans should alert members early on as to whether they are likely to exceed the gap.

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