Out-of-Pocket Spending for Insulin, Diabetes-Related Supplies, and Other Health Care Services Among Privately Insured US Patients With Type 1 Diabetes

Concern about high out-of-pocket spending for insulin has prompted states, payers, and pharmacy benefit managers to limit cost-sharing in the US.1,2 In addition to insulin, patients with type 1 diabetes might have out-of-pocket expenses for other care, such as diabetes-related supplies. Using national 2018 claims data, we estimated out-of-pocket spending for insulin and other health care services for privately insured patients with type 1 diabetes.

Methods | We analyzed 2018 data from the IBM MarketScan Commercial Database,3 which included patients with employer-sponsored coverage from medium to large firms. We included patients aged 1 to 64 years with continuous enrollment throughout 2018, 1 or more type 1 diabetes diagnosis code in 2017 (to limit the analysis to established patients), and 1 or more insulin claim in 2018. Because the data used were deidentified, the institutional review board of the University of Michigan Medical School did not regulate this study as human participant research; informed consent was not required.

We assigned inpatient, outpatient, and pharmacy claims in 2018 to 4 categories: (1) insulin, (2) diabetes-related supplies (eg, insulin pumps, glucometers), (3) other type 1 diabetes-related services (medications such as sulfonylureas and inpatient/outpatient claims with a type 1 diabetes diagnosis code), and (4) all other services not assigned to the first 3 categories (eg, visits for viral illness) (eAppendixes 1-4 in the Supplement). Based on whether patients had 1 or more claim for insulin pumps or associated supplies, and whether patients had...

### Table. Diabetes Technology Use and Annual Out-of-Pocket Spending Among Privately Insured Patients With Type 1 Diabetes

| Outcome | All patients (n = 65 192) | Children (n = 7842) | Adults (n = 57 350) | Patients enrolled in high-deductible health plansb | Yes (n = 14 680) | No (n = 50 512) |
|---------|--------------------------|---------------------|---------------------|-----------------------------------------------|-----------------|-----------------|
| Technology use, No. (%) |                          |                     |                     |                                               |                 |                 |
| Insulin pumps but not continuous glucose monitors | 8626 (13.2) | 1075 (13.7) | 7551 (13.2) | 1947 (13.3) | 6679 (13.2) |
| Continuous glucose monitors but not insulin pumps | 8083 (12.4) | 1391 (17.7) | 6692 (11.7) | 2052 (14.0) | 6031 (11.9) |
| Both insulin pumps and continuous glucose monitors | 20 333 (31.2) | 3698 (47.2) | 16 635 (29.0) | 4866 (33.2) | 15 467 (30.6) |
| Patients using neither insulin pumps nor continuous glucose monitors | 28 150 (43.2) | 1678 (21.4) | 26 472 (46.2) | 5815 (39.6) | 22 335 (44.2) |
| Out-of-pocket spending, US$ |                          |                     |                     |                                               |                 |                 |
| Insulin Mean (SD) | 435 (544) | 497 (664) | 427 (524) | 568 (667) | 397 (495) |
| Median (25th-75th percentile) | 315 (120-640) | 278 (100-554) | 375 (80-804) | 270 (105-501) |
| Diabetes-related suppliesc Mean (SD) | 490 (785) | 823 (977) | 445 (744) | 688 (988) | 433 (705) |
| Median (25th-75th percentile) | 446 (23-1306) | 80 (0-588) | 188 (0-1097) | 88 (0-589) |
| Other type 1 diabetes-related services Mean (SD) | 385 (788) | 510 (824) | 368 (781) | 542 (783) | 340 (783) |
| Median (25th-75th percentile) | 295 (153-592) | 174 (60-402) | 300 (94-645) | 168 (61-368) |
| All other servicesd Mean (SD) | 1103 (3248) | 468 (991) | 1190 (3434) | 1335 (1721) | 1036 (3569) |
| Median (25th-75th percentile) | 537 (164-1424) | 192 (52-515) | 613 (196-1560) | 698 (183-1899) | 502 (160-1297) |
| Overall Mean (SD) | 2414 (3531) | 2298 (1817) | 2420 (3704) | 3122 (1916) | 2205 (3851) |
| Median (25th-75th percentile) | 1993 (1055-3301) | 1977 (1038-3224) | 1995 (1056-3314) | 2904 (1770-4119) | 1764 (935-2958) |
| Overall out-of-pocket spending accounted for by insulin, % | 18.00 | 21.60 | 17.60 | 18.10 | 18.00 |

a Data from IBM Watson Health.3
b Based on whether the MarketScan plan type variable indicated enrollment in a consumer-driven health plan or qualified high-deductible health plan throughout 2018.

c Includes insulin pumps/supplies (eg, pump unit, infusion sets), continuous glucose monitors/supplies (eg, sensors, transmitters, receivers), glucometers/supplies (eg, meter, lancets, glucose strips), urine testing strips, blood ketone tests, needles, and syringes.
d Inpatient, outpatient, or pharmacy claims that were not for insulin, diabetes-related supplies, or other type 1 diabetes-related services.
1 or more claim for continuous glucose monitors or associated supplies, we classified patients as using pumps only, continuous glucose monitors only, both, or neither.

For each category, we calculated the mean (SD) and median annual out-of-pocket spending. We calculated the proportion of annual overall out-of-pocket spending accounted for by insulin. We also calculated out-of-pocket spending for diabetes-related supplies according to use of insulin pumps and continuous glucose monitors.

In subgroup analyses, we stratified by age (children aged 1 to 17 years vs adults aged 18 years or older) and enrollment in a high-deductible health plan, defined as qualified high-deductible health plans with statutorily defined minimum deductibles of US $1350 for individual and US $2700 for family coverage in 2018 or consumer-driven health plans that typically couple high deductibles with health reimbursement arrangement accounts.4

Results | The 65,192 patients who met the inclusion criteria had a mean (SD) age of 40.8 (16.5) years and included 7842 children (12.0%), 30,133 women (46.2%), and 14,680 individuals (22.5%) enrolled in high-deductible health plans. Overall, 37,042 patients (56.8%) used insulin pumps, continuous glucose monitors, or both.

The use of diabetes technologies and annual out-of-pocket spending are shown in the Table. Mean (SD) annual out-of-pocket spending for insulin was lower ($435 [$544]) than spending for diabetes-related supplies ($490 [$785]). Mean (SD) annual overall out-of-pocket spending was $2414 ($3531); for 5191 patients (8.0%), this spending exceeded $5000. Insulin accounted for 18.0% of overall out-of-pocket spending. Mean (SD) annual out-of-pocket spending for diabetes-related supplies varied among patients who used insulin pumps only ($562 [$626]), continuous glucose monitors only ($472 [$625]), both ($1037 [$1039]), or neither ($79 [$175]).

Compared with adults, children had higher use of diabetes technologies and higher out-of-pocket spending for diabetes-related supplies (Table). Among children, out-of-pocket spending for diabetes-related supplies ($823) was higher than for insulin ($497) (Figure). Among adults, out-of-pocket spending for diabetes-related supplies ($445) and insulin ($427) were similar. Patients enrolled in high-deductible health plans had higher out-of-pocket spending in each category than patients enrolled in other plans (Table).

Discussion | In a national sample of privately insured patients with type 1 diabetes, mean out-of-pocket spending for all care was nearly $2500 in 2018. For 8% of patients, this spending exceeded $5000. Insulin accounted for 18% of all out-of-pocket spending and less out-of-pocket spending than diabetes-related supplies. Findings suggest that substantial out-of-pocket burden may remain for patients with type 1 diabetes even if insulin cost-sharing is limited. Government officials and insurers should consider improving coverage for all type 1 diabetes-related services, following the approach of a 2019 rule allowing qualified high-deductible health plans to cover services such as insulin and glucometers before deductibles are met.5

This study has limitations. We did not study patients covered by Medicare or Medicaid or those without insurance. The data-base included patients who received insurance from medium to large firms,3 which typically offer plans with lower deductibles compared with plans offered by small firms.6 Consequently, findings may underestimate out-of-pocket spending for patients with type 1 diabetes who receive insurance from small firms.

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