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Improving Quality of Patient Educational Materials through a Comparative Analysis of Patient Handbooks from U.S. Transplant Centers

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Purpose: Educational materials provided to transplant patients are usually center- and organ-specific, variable in content and quality, and often not evidence based. A patient-founded transplant nonprofit, in collaboration with major academic transplant centers, a leading research university, and a prominent healthcare technology company, sought to analyze the scope and quality of transplant patient educational materials to inform and promote best patient-centered practices in transplantation.

Methods: The educational handbooks provided to adult solid organ transplant candidates and recipients (heart, kidney, liver, lung, and pancreas) were collected from 23 U.S. centers, including 80% of the nation's 20 largest centers based on 2023 volume. Using Natural Language Processing and Generative Artificial Intelligence, Transplants.org and Carnegie Mellon University, supported by pro bono technical expertise from Oracle, parsed the text and tables from each handbook, organized them into structured formats, and processed the outputs through a proprietary generative AI model for advanced comparative analysis of both content and quality.

Results: A total of 100 handbooks were analyzed. Topics in common included symptoms of rejection and other post-transplant complications, management of immunosuppression side effects, and follow-up testing. Conversely, inclusion of topics such as reproductive health, routine health maintenance, and financial counseling was variable. Additionally, there was significant variability in the content of education on topics like medications to avoid and lifestyle decisions such as traveling, nutrition, and mask usage. Recommended guidance for Eating Out at Restaurants (Table 1), for example, was decidedly varied: Yes, *with Exceptions* (36%), No (32%), or *Unsure/Unclear* (32%).

Conclusions: Educational materials provided to adult transplant candidates and recipients demonstrate significant variability in content and quality, often creating conflicting or insufficient guidance on important topics. Our findings suggest an opportunity to enhance and standardize patient education to reduce patient confusion and improve post-transplant outcomes. We advocate for a centralized repository of common educational materials updated regularly by key stakeholders including transplant leaders, patients, and caregivers, and digital distribution by transplant centers.

Table 1: Variation in Patient Guidance for Eating Out at Restaurants

Organ Handbook Type	Overall Responses (n=100)	Yes, with Exceptions	No	Unsure/Unclear
Heart	26 (26.0%)	7 (26.9%)	11 (42.3%)	8 (30.8%)
Kidney	22 (22.0%)	7 (31.8%)	6 (27.3%)	9 (40.9%)
Liver	15 (15.0%)	7 (46.7%)	4 (26.7%)	4 (26.7%)
Lung	26 (26.0%)	9 (34.6%)	8 (30.8%)	9 (34.6%)
Pancreas	11 (11.0%)	6 (54.5%)	3 (27.3%)	2 (18.2%)
All	100 (100%)	36 (36.0%)	32 (32.0%)	32 (32.0%)