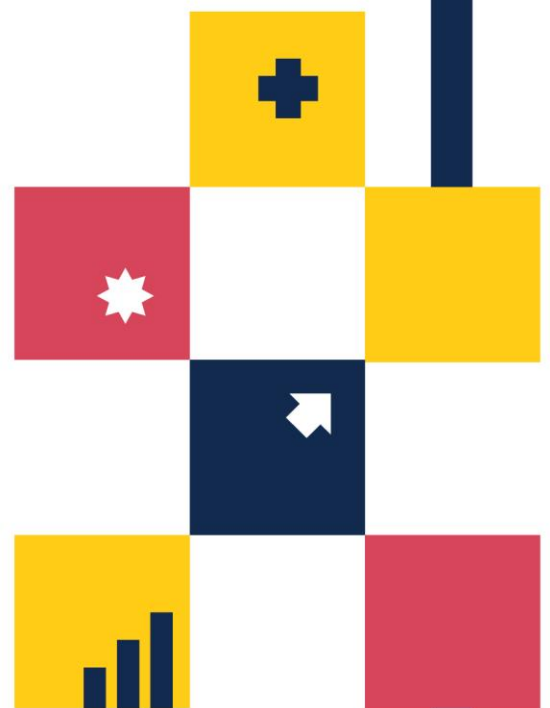


Financial Restrictions on Access to Organ Transplants

December 2022





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Executive Summary

The General Assembly requested, through a budget resolution, that the Maryland Health Care Commission (MHCC) submit a report that reviews the existing policies governing the eligibility for receiving an organ donation, identifies reasons for denial of organ transplantation, and includes the number of individuals who had organ transplant needs denied or deferred under each reason since calendar year 2018. This request was driven by a concern that financial requirements for organ transplant candidates may be a cause of denial or deferral of care in Maryland.

MHCC staff requested and reviewed the organ transplant policies of The Johns Hopkins Hospital (JHH), University of Maryland Medical Center (UMMC), and MedStar Georgetown Transplant Institute (MGTI). Staff concluded that the current policies of JHH, UMMC, and MGTI are consistent with federal regulations that require an assessment of the financial support available for a patient. The hospitals' policies do not include a rigid set of criteria, such as specific financial targets or documentation of assets, that could be perceived as discriminatory and burdensome to some organ transplant candidates. While the policies of hospitals may not directly create financial barriers for organ transplant candidates, additional research on the practices of hospitals and the perception of patients who do not follow through with the process for gaining access to an organ transplant waitlist may provide further insight.

MHCC staff concluded that additional research is also needed to provide further insight into whether hospitals' financial screening processes are hindering access to organ transplant waitlists. While it does not appear to be an issue based on the descriptions provided by JHH, UMMC, and MGTI, additional information would be very beneficial. MHCC staff were unable to obtain complete information on how often and why patients are not accepted onto an organ transplant waitlist at UMMC, JHH, or MGTI. This information is needed for an accurate understanding of the extent to which a lack of financial resources is a barrier to an organ transplant for Maryland residents.

MHCC staff concluded that patients do not appear to be removed from organ transplant waitlists at Maryland hospitals for financial reasons, once listed. Information reported by JHH indicates no patients were removed for financial reasons, and less than one percent were removed for insurance complications. UMMC reported that no patients were removed for financial reasons.

MHCC staff recommends the State conduct additional research, such as surveying or interviewing patients who both do and do not pursue an organ transplant following referral from a physician. It would be especially useful to include patients who begin the process for getting on an organ transplant waitlist at UMMC, JHH, or MGTI, but who do not complete it. Any additional research should focus on the extent to which financial barriers and other social determinants may affect patients' pursuit of an organ transplant.



I. Introduction

The General Assembly requested, through a budget resolution, that the Maryland Health Care Commission (MHCC) submit a report that reviews the existing policies governing the eligibility for receiving an organ donation, identifies reasons for denial of organ transplantation, and includes the number of individuals who had organ transplant needs denied or deferred under each reason since calendar year 2018. This request was driven by a concern that financial requirements for organ transplant candidates may be a cause of denial or deferral of care in Maryland. For a copy of the budget language, refer to Appendix A.

Federal regulations, 42 CFR § 482.90, require that a transplant program must use written patient selection criteria in determining a patient's suitability for placement on the waiting list or a patient's suitability for transplantation. These federal regulations specify in §482.90 (a)(1) that "Prior to placement on the program's waiting list, a prospective transplant candidate must receive a psychosocial evaluation, if possible." The Centers for Medicare and Medicaid's State Operations Manual that provides guidance for surveyors of organ transplant programs states that hospitals have flexibility in selection of the evaluation tool used, but the evaluations should include at a minimum the following¹:

- *Social, personal, housing, vocational, financial, and environmental supports;*
- *Coping abilities and strategies;*
- *Understanding of the risks and benefits of transplantation;*
- *Ability to adhere to a therapeutic regimen; and*
- *Ongoing psychological issues that may impact the success or failure of organ transplantation.*

MHCC staff requested organ transplant policies between January 2018 and present from the two transplant programs in Maryland: The Johns Hopkins Hospital (JHH) and the University of Maryland Medical Center (UMMC).² Additionally, MHCC staff reviewed current policies from MedStar Georgetown University Transplant Institute (MGTI), located in the District of Columbia, because MedStar Health provides organ transplantation services to Maryland residents. MHCC staff also met with representatives for JHH, UMMC, and MGTI to obtain additional information and clarification on the process for organ transplant candidates referred to their programs.

¹ State Operations Manual. Appendix X – Guidance to Surveyors: Organ Transplant Programs (Rev. 200, Issued: 02-21-20) X-053.

² Both UMMS and JHH provided statements that the hospitals' organ transplant policies are confidential and provided copies of the policies in a manner that allowed MHCC staff to read the policies, but not copy or save them.



Background

There are significant costs related to organ transplantation. The average Maryland hospital charges in CY 2021 for organ transplants, were approximately \$150,000 for a kidney, \$234,000 for a pancreas, and \$500,000 for a heart and/or lung transplant.³ Those charges do not include physician and other health care professional services billed separately from the hospital facility charges. A report from the actuarial firm, Milliman, includes estimated billed charges for organ transplant patients in the United States from 30 days prior to an organ transplant to 180 days after a transplant.⁴ This report shows the average charges for a heart transplant exceed \$1.5 million dollars and for a liver transplant exceed \$800,000.⁵ For a kidney transplant or pancreas transplant the average billed charges are around \$400,000.⁶ These estimated charges reflect that an organ transplant itself is not the only expense for organ transplant recipients.

There are substantial pre- and post-transplant charges as well. UMMC noted that post-transplant patient expenses include pharmaceuticals for immunosuppression, follow-up visits, testing, and routine biopsies. UMMC cited cost estimates for immunosuppression drugs for various organs for the period from a hospital admission through the first six months post-transplant as follows: heart \$39,000; kidney \$31,000; liver \$38,000; and pancreas \$26,500.⁷ Even with insurance, UMMC noted that deductibles, co-pays, and co-insurance payments can result in significant additional out-of-pocket expenses for transplantation patients.

The organ transplant process is lengthy, with the pre-transplant evaluation process spanning months, and patients may need to be re-evaluated periodically. UMMC explained that a kidney transplant candidate for example, may remain on a waitlist for three to eight years.

As required by national certification standards,⁸ part of the pre-transplant evaluation process involves a mandatory psychosocial evaluation to assess the financial support available

³ MHCC staff analysis of HSCRC discharge data for CY 2021 using APR-DRG codes to identify organ transplants.

⁴ Note: Maryland hospital charges constitute what hospitals were paid, the Milliman report presents billed charges, in most cases the total reimbursed amount, reflecting the payer payment and the patient cost sharing will be less than the billed amount.

⁵ Milliman Research Report. “2020 U.S. Organ and Tissue Transplants: Cost estimates, discussion and emerging issues.” Prepared by Scott Bently and Nick Ortner (January 2020).

⁶ Milliman Research Report. “2020 U.S. Organ and Tissue Transplants: Cost estimates, discussion and emerging issues.” Prepared by Scott Bently and Nick Ortner (January 2020).

⁷ Milliman Research Report. “2020 U.S. Organ and Tissue Transplants: Cost estimates, discussion and emerging issues.” Prepared by Scott Bently and Nick Ortner (January 2020). <https://www.milliman.com/-/media/milliman/pdfs/articles/2020-us-organ-tissue-transplants.ashx>

⁸ State Operations Manual. Appendix X – Guidance to Surveyors: Organ Transplant Programs (Rev. 200, Issued: 02-21-20) X-053.



to patients. As explained by one transplant program reviewed, organ transplant programs also have an incentive to confirm that patients can afford post-transplant expenses because the post-transplant care is critical to a successful transplant and patient survival. The Centers for Medicare and Medicaid Services (CMS) evaluate an organ transplant program’s performance, as measured by graft and patient survival.⁹ This evaluation is publicly available and posted on the Scientific Registry of Transplant Recipients website.¹⁰ Commercial insurance networks typically review a participating program’s performance and compare it to national benchmarks for one-year and three-year survival rates in deciding whether to continue to include a transplant program in its network.¹¹ UMMC, JHH, and MGTI all expressed the sentiment that its program seeks to ensure that patients have adequate financial resources for successful post-transplant management in order to be a good steward of organs, a scarce resource.

II. Research Findings

Review of Hospital Organ Transplant Policies

MHCC staff concluded that the current policies of JHH, UMMC, and MGTI are consistent with federal regulations that require an assessment of the financial support available for a patient seeking transplant services. These hospitals’ policies do not include a rigid set of criteria, such as specific financial targets or documentation of assets that could be perceived as discriminatory and burdensome to some organ transplant candidates. While the policies of hospitals may not directly create financial barriers for organ transplant candidates, additional research on the practices of hospitals and the perception of patients who do not follow through with the process for accessing the organ transplant waitlist may provide further insight.

MHCC staff reviewed the policies concerning listing of organ transplant candidates of JHH, UMMC, and MGTI. There are separate policies for each of the types of organ transplants performed at each location. The approaches taken by each of the three hospitals, as stated in policies and determined through speaking with representatives for each program, are substantially similar with respect to evaluating eligibility. Each policy lists specific medical tests or evaluations to be conducted or considered, medical and psychosocial criteria indicative of eligibility, and criteria that may contraindicate organ transplant eligibility. Both JHH and UMMC also frequently note criteria that may be relative, but not absolute contraindications for an organ transplant, that will be considered in decisions regarding waitlisting of organ transplant candidates.

JHH, UMMC, and MGTI all screen candidates for financial eligibility before starting the evaluation of the patient’s health or psychosocial assessment. This is sometimes stated

⁹ Centers for Medicare and Medicaid. “Transplant.” <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Transplant>

¹⁰ <https://www.srtr.org/>.

¹¹ Email correspondence with David Marozzi, M.D. to Eileen Fleck, September 2, 2022.



directly in a hospital's policy for a specific type of organ. MHCC staff reviewed policies provided and focused on whether the organ transplant policies of JHH, UMMC, and MGTI differed with respect to financial eligibility criteria. MHCC staff also noted whether financial eligibility criteria differed across organ transplant policies at a single hospital or whether criteria had changed between January 2018 and the present. The history of policy changes for all of the programs is unknown in some cases. A more detailed description of the review of policies for JHH, UMMC, and MGTI follows.

Johns Hopkins

It does not appear that JHH has changed its policies regarding financial eligibility criteria since January 2018; however, JHH only provided its current organ transplant policies. While these documents include information on the history of revisions and sometimes briefly note how policies changed in each update, MHCC staff cannot confirm that no changes or only minor changes were made to financial criteria without directly reviewing the documents.

With respect to JHH's criteria for listing an organ transplant candidate, the policies for a kidney, pancreas, liver, heart, or lung transplant all include an evaluation of financial resources as a criterion, but the way this evaluation is referenced differs sometimes. For example, the lung transplant policy treats the evaluation of financial resources as part of the psychosocial evaluation without much additional detail, but the liver transplant policy notes that the patient evaluation will include an evaluation of income, the ability to meet transplant expenses, and the employment status of the candidate and caregiver. The liver policy also separately notes there will be an assessment of insurance coverage including prescription coverage for post-transplant medications. In contrast, for kidney and pancreas transplants, the policy states that "Financial evaluation/clearance" is required, without additional specificity. For a heart transplant candidate, the policy states that a psychosocial evaluation is required that includes an evaluation of financial support. The minor differences in language do not appear to reflect substantive differences in the financial criteria or process used to evaluate candidates for the organ transplant waitlist.

Once a patient has been added to an organ transplant list, management of the patient on the waitlist varies by organ type and by how soon a patient is likely to be near the top of the organ transplant list. For example, an adult liver transplant patient will be re-evaluated clinically every 18 months, but more often if needed. The policy states that for patients above a specific MELD¹² threshold, follow-up should be more frequent. However, in terms of the psychosocial evaluation, including the consideration of financial issues, if no new issues are identified, it is only repeated at five-year intervals. For a heart transplant patient, JHH will conduct an annual reassessment including the psychosocial evaluation. For kidney transplant

¹² MELD stands for "model for end-stage liver disease." It is a measure of the severity of liver disease.

candidates, who are not expected to be near the top of the waitlist within a year, psychosocial evaluations will be conducted every two years.

University of Maryland

Between January 1, 2018 and the present, UMMC has not changed its policies with respect to screening organ transplant candidates first for financial eligibility.¹³ However, UMMC reported that it revised its policies to assure consistency across different organ transplant types in the most recent updates. MHCC staff noted, in its initial review of UMMC policies, that only some of the liver transplant policies explicitly stated that candidates will be screened for financial eligibility prior to further evaluation. This language is not included in the current policy, but it was included in the previous policy. In addition, even though the policy language changed, UMMC confirmed that the current practice is for candidates for all types of organ transplants to be screened to determine the adequacy of financial resources, which includes insurance coverage.¹⁴

UMMC's prior versions of the liver, pancreas, and kidney transplant policies (2018-2021) all included "inadequate financial resources" among the list of contraindications for these transplants. For lung transplants, the prior policies in place during 2018 through 2021 indicated that a patient must demonstrate realistic plans to handle the costs associated with the transplant through insurance, funding raising, family support, or other means. In the current policies for all organs, "inadequate financial resources" is included among the list of relative contraindications, suggesting that adequate financial resources are not an absolute requirement for adding a patient to the transplant lists. Relative contraindications are those that may be a reason that a patient is inappropriate for a transplant, but which are not absolutely contraindications for a transplant; the specific circumstances for each patient must be considered.

Since 2018, the heart transplant policies have not changed with respect to financial criteria. Lack of adequate financial support has consistently been on the list of relative contraindications for heart transplant candidates.

MedStar Georgetown

MedStar Health provided a copy of its current policies for intestine, pancreas, kidney, and liver transplants. MHCC staff does not know with certainty how policies may have changed since January 2018. In all four of the policies, it is stated that financial clearance is required before continuing with the next steps of the evaluation process. For kidney and intestine transplants, there are no contraindications or relative contraindications included in the

¹³ Email correspondence from Daniel G. Maluf, M.D. to Eileen Fleck, December 5, 2022.

¹⁴ Presentation provided by Daniel G. Maluf, M.D. to MHCC staff on October 18, 2022.



policies pertaining to medical criteria or psychosocial criteria. There are only indications for a transplant. However, the pancreas transplant policy describes medical indications for a transplant, and the list of contraindications includes “inadequate insurance or finances.” The liver transplant policy also has a list of contraindications, and finances are not specifically mentioned; only the “presence of adequate psychosocial support as determined by social service and psychiatry consultants” is mentioned.

Staff Analysis

Across all three hospitals, ensuring that transplant candidates have adequate financial resources for an organ transplant is a high priority. As described by JHH, UMMC, and MedStar Health, this evaluation is not accomplished through pre-set requirements for income or savings or the submission of proof of financial resources. The evaluation of financial resources available to a patient is intended to give patients a realistic idea of potential costs and obstacles to successful transplantation. The hospitals state that their social workers, counselors, or other hospital staff work with patients to overcome barriers identified, when possible.¹⁵ Hospital staff serve a supporting role and patients or those who are a part of a patient’s social support system may need to be responsible for following through on some suggestions.¹⁶ MHCC staff’s understanding is that hospitals try to give patients a greater sense of agency over their health care decisions through educating them on anticipated expenses and resources that may help them to handle those expenses. The level of support for organ transplant patients in this regard is unique and not routinely available to patients with many other health conditions.¹⁷

The hospitals justify consideration of financial resources of patients by highlighting the importance of making the best use of available organs, given demand far exceeds the supply of organs available, and the expense of the required post-transplant drugs to ensure the organ is not rejected. MHCC staff concluded that hospitals do have a strong rationale for considering whether organ transplant candidates’ have adequate financial resources. As described by hospitals, it does not appear the policies are implemented in a way that excessively hinders organ transplant candidates’ access to organ transplant waitlists.

Hospitals’ Evaluation of the Financial Resources of Organ Transplant Candidates

MHCC staff concluded that additional research is needed to provide further insight into whether hospitals’ financial screening processes are hindering access to organ transplant waitlists. While it does not appear to be an issue based on the descriptions provided by JHH, UMMC, and MGTI, additional information would be very beneficial. Additional research

¹⁵ Email correspondence from Daniel C. Brennan, M.D. to Eileen Fleck on September 6, 2022; Meeting with representatives for UMMC and MHCC staff on October 18, 2022; Conversation between Anne Weiland and Eileen Fleck on October 24, 2022.

¹⁶ Conversation between Anne Weiland and Eileen Fleck on October 24, 2022.

¹⁷ Conversation between Anne Weiland and Eileen Fleck on October 24, 2022.



should focus on patients’ perceptions of the process and factors influencing patients’ decisions both to pursue or not pursue an organ transplant. A description of the information requested and provided by each hospital follows.

JHH, UMMC, and MedStar Health all reported that screening of organ transplant candidates includes a review of financial resources. In all cases, this appears to primarily consist of determining if a patient has health insurance with benefits that cover organ transplant expenses. JHH specifically noted that it checks whether patients have both transplant benefits and prescription coverage benefits.¹⁸ JHH noted that if a patient is out-of-network or a procedure would require a large out-of-pocket payment, the financial coordinator makes the patient aware of this expense and helps the patient to determine whether to pursue a transplant at JHH or another center that is in the patient’s insurance carrier’s provider network.¹⁹ Similarly, UMMC follows the same process.²⁰ JHH does not require or request documentation of personal financial information or discussion of a patient’s level of income.²¹ Similarly, UMMC and MGTI described their screening processes as a determination of whether a patient has insurance, including prescription drug coverage.²² UMMC stated that it does not have specific financial requirements before proceeding with the evaluation of an organ transplant candidate.²³ MedStar Health also conveyed that it does not have specific financial requirements; it does not request information to verify a patient’s income or savings.²⁴

In addition to explaining its screening process for organ transplant candidates, MGTI provided a copy of its, “Financial guide for organ transplant patients and their families.”²⁵ This brochure explains the importance of insurance to cover costs before, during, and after an organ transplant. It also includes answers to four frequently asked questions. These questions address the following: what if I do not have enough health insurance coverage; if I have Medicare, am I covered for everything; who should I contact if anything about my insurance changes; and what about my prescription coverage. MGTI also provided a diagram of the financial screening process for a liver transplant candidate, showing how the type of insurance or having no insurance influences the next steps in the process.²⁶

The information provided by JHH, UMMC, and MGTI indicates that the ability of patients to cover the costs of a transplant are a primary and critical consideration. In each case,

¹⁸ Email correspondence from Daniel C. Brennan, M.D. to Eileen Fleck, November 9, 2022.

¹⁹ Ibid.

²⁰ Email correspondence from Daniel G. Maluf, M.D. to Eileen Fleck, December 12, 2022.

²¹ Ibid.

²² Meeting with representatives for UMMC and MHCC staff on October 18, 2022; Conversation between Anne Weiland and Eileen Fleck on October 24, 2022.

²³ Presentation by Daniel G. Maluf, M.D. provided to MHCC staff on October 18, 2022.

²⁴ Conversation between Anne Weiland and Eileen Fleck on October 24, 2022.

²⁵ Email correspondence from David C. Tobin to Ben Steffen on September 27, 2022.

²⁶ Email correspondence from Anne Weiland to Eileen Fleck on October 25, 2022.

the hospital must conclude that a patient has adequate financial resources or is likely to obtain adequate financial resources before proceeding with other steps. If a potential organ transplant candidate, or the hospital, concludes that an organ transplant is financially out of reach, whether other criteria can be met or not becomes irrelevant.

Impact of Financial Resources on Waitlisting

MHCC staff concluded that the lack of complete information on how often and why patients are not accepted onto an organ transplant waitlist at UMMC, JHH, or MGTI is a barrier to accurately understanding the extent to which a lack of financial resources is a barrier to an organ transplant for Maryland residents. A description of the information requested and obtained from each hospital follows.

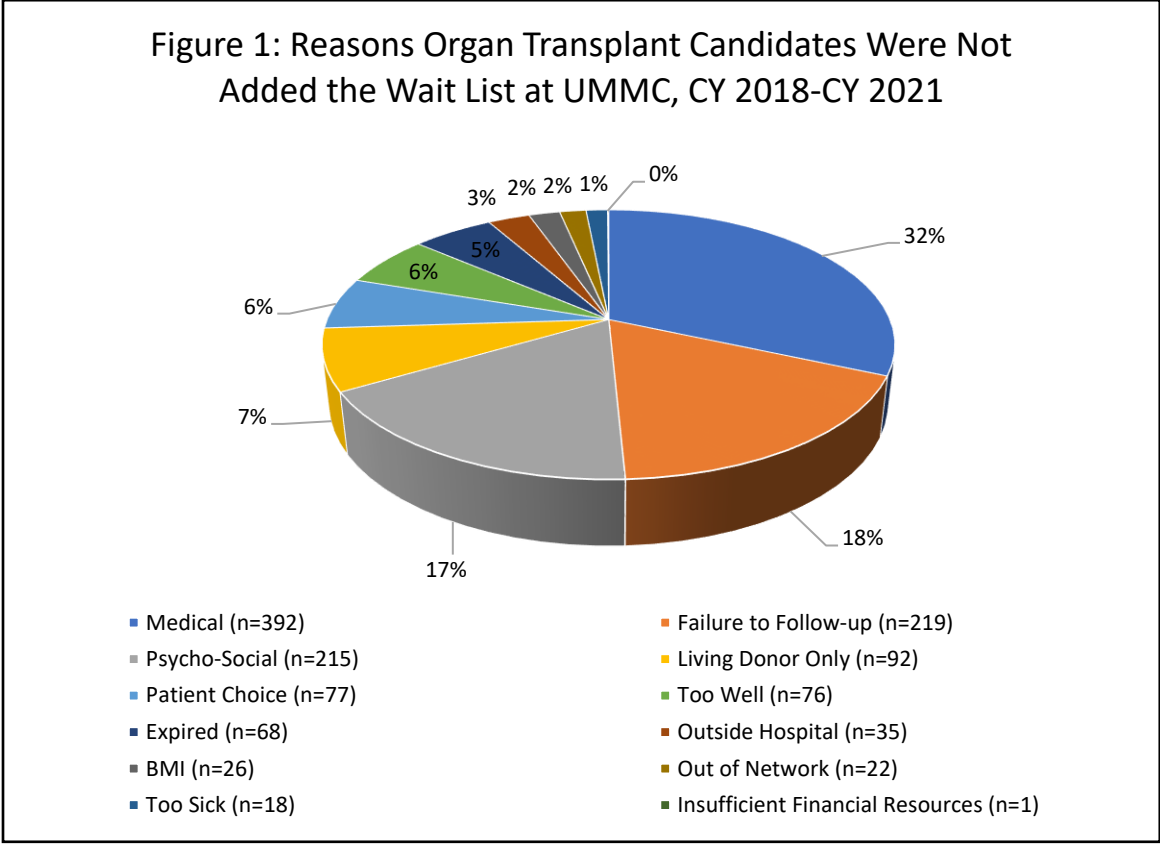
When asked about the number of organ transplant candidates who were not accepted onto an organ transplant waitlist and the reasons for it, UMMC and MGTI both reported difficulty with providing this information. UMMC reported that information on the reasons patients were not waitlisted at the hospital was available for only 1,240 candidates out of approximately 3,000 evaluated but not listed between January 2018 and December 2021. UMMC explained that due to changes in the electronic medical record systems, reliable information could not be provided for many candidates evaluated.²⁷ Of the 1,240 candidates with accessible information, UMMC reported that only one was identified as having insufficient financial resources.²⁸ The full range of reasons why organ transplant candidates were not waitlisted at UMMC, and the distribution of those reasons for the period from January 2018 through December 2021, are shown in Figure 1. As shown in Figure 1, the most common reasons organ transplant candidates declined to be waitlisted at UMMC were “Medical”, followed by “Failure to Follow-up,” and “Psycho-Social.”

²⁷ Presentation of Daniel G. Maluf, M.D. to MHCC staff on October 18, 2022.

²⁸ Email correspondence from David Marcozzi, M.D. to Eileen Fleck, September 2, 2022.



Figure 1: Reasons Organ Transplant Candidates Were Not Added the Wait List at UMMC, CY 2018-CY 2021



Source: Presentation by Daniel G. Maluf, M.D. to MHCC staff on October 18, 2022

UMMC noted that, as of October 1, 2022, it has established a process for creating an electronic report regarding individuals who were not listed as a transplant candidate after being referred to UMMC.²⁹ This information is essential for providing a more accurate assessment of the reasons organ transplant candidates were not added to an organ transplant list at UMMC. UMMC was able to provide a reason for less than half of the patients evaluated, but not added to its organ transplant waitlist, for the four-year period requested.

JHH reported that between January 1, 2018 and July 25, 2022, it received a total of 10,532 referrals and 774 patients (7%) were ineligible for financial/insurance reasons.³⁰ JHH explained that the reasons were essentially tied to insurance and included the following: the patient’s insurance does not participate at JHH, the patient’s insurance was out-of-state medical assistance, the patient has a higher-level benefit at another transplant center, and patient choice.

²⁹ Presentation of Daniel G. Maluf, M.D. provided to MHCC staff on October 18, 2022.
³⁰ Email correspondence from Daniel C. Brennan, M.D. to Eileen Fleck, September 6, 2022.



MHCC staff asked UMMC and JHH about the number of transplant candidates who were referred, or who were qualified, and received financial support based on the hospital’s policies for financial assistance annually, for the period from January 1, 2018 through December 31, 2021. Only JHH hospital was able to provide this information. Table 1 shows the number of patients and total amount of financial assistance for calendar years 2018 through 2021 and the available information for 2022. Over the entire period shown in Table 1, there were 99 organ transplant patients who received financial assistance.

**Table 1: Financial Assistance
for Organ Transplant Recipients at JHH by Year**

Year	Number of Patients	Total Amount of Financial Assistance
2018	21	181,379
2019	24	41,747
2020	23	19,946
2021	13	23,081
2022	18	281,249

Source: John Hopkins Hospital's analysis of financial data, January 1, 2018 through November 11, 2022.

Note: Financial assistance included in the table is for hospital expenses (facility fees, room and board, pharmacy, and ancillary costs); the table only includes financial assistance available to patients based on JHH's financial assistance policies for all patients. Total amount of financial assistance is rounded to the nearest dollar.

UMMC explained that financial support provided to organ transplant patients is not tracked specifically for organ transplant candidates, and it has not been a regulatory requirement; however, UMMC stated that it would keep a record of those requests going forward. MGTI did not provide the statistical information requested either.

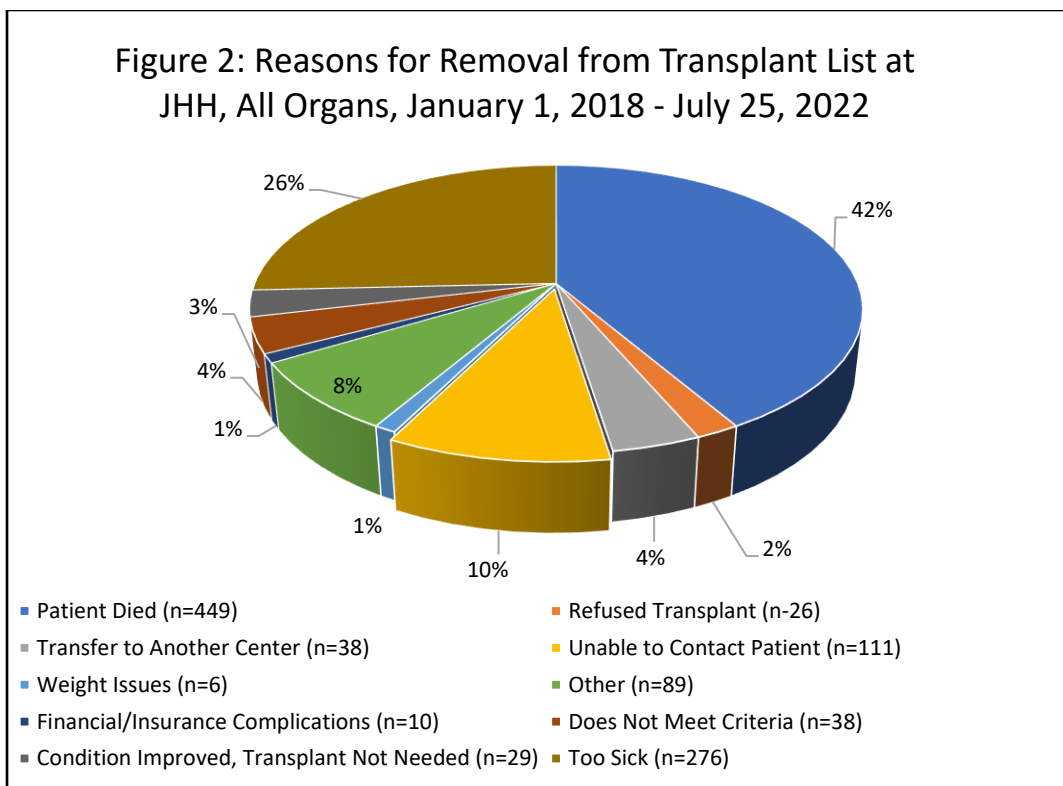
Removal from Organ Transplant Waitlists for Financial Reasons

MHCC staff concluded that patients do not appear to be removed from organ transplant waitlists at Maryland hospitals for financial reasons once listed, based on information reported by JHH and UMMC. The information provided by JHH and UMMC is described in greater detail below.

MHCC staff requested data on the number of patients who were moved off an organ transplant waitlist and the reasons for removal from the waitlist for the period from January 1, 2018 through December 31, 2021 (or later if known). JHH responded that between January 1, 2018 and July 25, 2022, there were a total of 1,072 patients removed from the waitlist. As shown in Figure 2 below, the most frequent reason cited, for 42% of patients, was “Patient



Died” (449 patients). Only ten patients, or about 1% of patients were removed for “Financial/Insurance Complications.” JHH noted that this category refers to insurance issues, not wealth or income considerations. However, for about 10% of patients the hospital was unable to contact the patient. For these patients who left the waitlist, it is unknown what factors may have contributed to their removal from the waitlist.

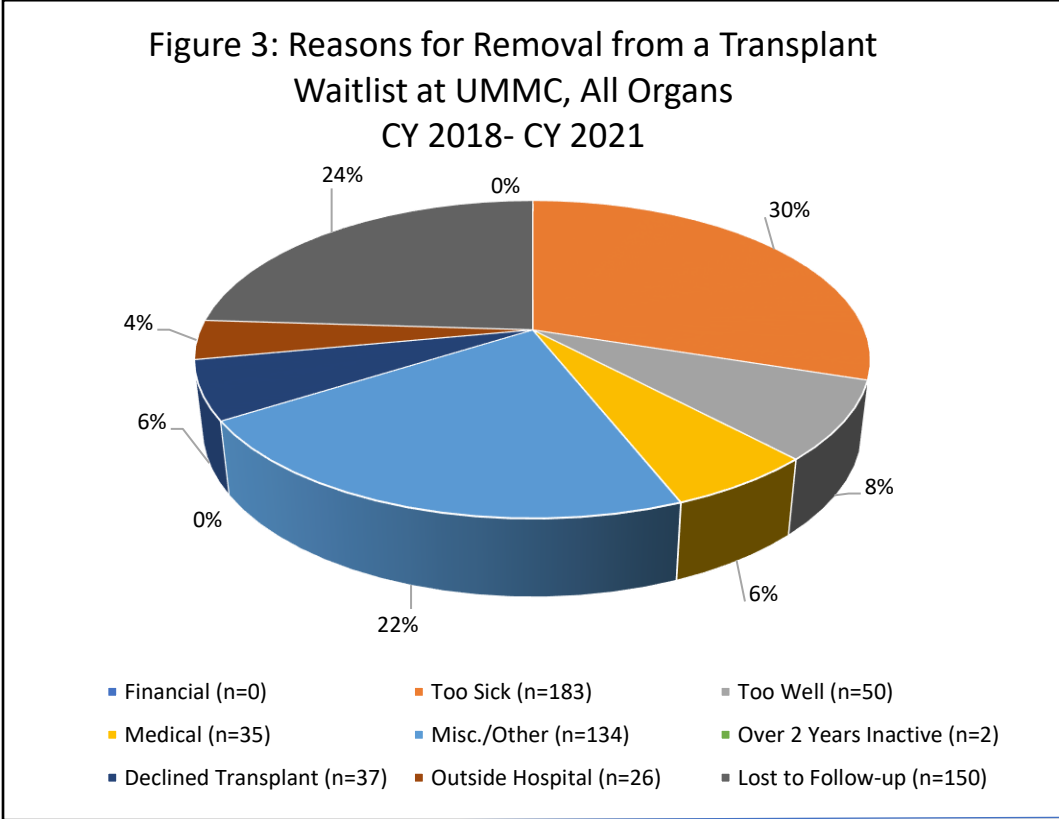


Source: Email correspondence from Daniel C. Brennan, M.D. to Eileen Fleck, November 9, 2022.

UMMC, like JHH provided information on reasons for an organ transplant candidate being removed from a waitlist that suggests financial reasons for removal are rare. As shown in Figure 3 below, UMMC reports that, for the period of January 1, 2018 through December 31, 2021, there were no patients removed for financial reasons. UMMC explained that, “UMMC Transplant Financial Coordinators assist candidates in maintaining resources to assure they are not removed from the waitlist for financial reasons.”³¹ The most frequent reason for removal from the waitlist identified by UMMC was “Too Sick,” which comprised the reason for 30% of patients removed. However, there were also 24% of patients removed who were “Lost to Follow-up.” This creates some uncertainty about what factors may have contributed to removal of these patients from the waitlist.

³¹ Email correspondence from David Marcozzi, M.D. to Eileen Fleck, September 2, 2022.





Source: Presentation by Daniel G. Maluf, M.D. to MHCC staff on October 18, 2022; and additional Information emailed by Dr. Maluf to Eileen Fleck on December 5, 2022.

Unlike JHH and UMMC, MedStar Health was unable to provide statistical information on the reasons for removal from the waitlist at MGTI. MedStar Health noted that when candidates move off the waitlist, the primary reasons are medical.³² It noted that occasionally there is a temporary deferral, which means inactivation but not removal from the list, due to a change in insurance plan.³³ MedStar Health reported that building a static report would be extremely onerous and that it is of no practical use for program management.³⁴

III. Conclusions

The lack of complete information on how often and why patients are not accepted onto an organ transplant waitlist at UMMC, JHH, or MGTI is a barrier to accurately understanding the extent to which a lack of financial resources is a barrier to an organ transplant for Maryland

³² Email correspondence from David C. Tobin to Ben Steffen September 27, 2022.
³³ Ibid.
³⁴ Ibid.



residents. The current policies of UMMC, JHH, and MGTI regarding consideration of financial resources of patients are consistent with federal regulations regarding the required content of the psychosocial evaluation of organ transplant candidates.

For patients who have already been added to a hospital's organ transplant waitlist, both UMMC and JHH reported complete information on reasons for removal for the period requested. As should probably be expected, given screening occurs early in the evaluation process for organ transplant listing, it appears to be rare that patients are removed from the waitlist due to a lack of financial resources. UMMC reported that no patients were removed for financial reasons. JHH reported that no patients were removed for financial reasons, only for insurance issues, which still included only about 1% of patients. However, there was also a significant percentage of patients who failed to follow-up, and it is possible that financial reasons could be contributing to patients' failing to follow-up or indirectly to other reasons for removal from the waitlist.

MHCC staff's review of hospitals' policies suggests that these policies do not excessively hinder organ transplant candidates access to organ transplant waitlists. The hospitals' policies do not contain specific financial benchmarks, and it does not appear that hospitals expect patients to provide proof of savings or income in the financial screening process. Nevertheless, it is possible that, for some transplant patients, the knowledge of the steep costs to expect could be a deterrent that leads to self-selection out of the process for getting on an organ transplant waitlist. This may be very difficult to measure. As previously noted, information provided by the two Maryland-based transplant programs is not sufficiently detailed to determine whether a patient may be able to get an organ transplant at another nearby hospital with less out-of-pocket expenses or whether a patient may lack the necessary financial resources to receive approval at any nearby transplant program.³⁵

MHCC staff recommends the State conduct additional research, such as surveying or interviewing patients who both do and do not pursue an organ transplant following referral from a physician. It would be especially useful to include patients who begin the process for getting on an organ transplant waitlist at UMMC, JHH, or MGTI, but who do not complete it. Any additional research should focus on the extent to which financial barriers and other social determinants may affect patients' pursuit of an organ transplant. The extent to which multiple factors play a role for individuals referred for an organ transplant and the relative importance of these factors could not be assessed by MHCC staff based on the information provided by UMMC, JHH, and MGTI.

³⁵ JHH and UMMC noted the challenges of treating a patient insured by an out-of-state Medicaid program. In most cases the patient would be referred to a transplant program in the patient's home state since Maryland hospitals would not be in-network with the out-of-state Medicaid program.

Appendix A: Legislative Study Request

M00R01
Health Regulatory Commissions
Maryland Department of Health

Financial Restrictions on Access to Organ Transplant Lists:

The committees are concerned that transplant hospitals have implemented policies that place financial restrictions on individuals eligible for receiving organ donations. Specifically, the committees are concerned with the consideration of means to cover aftercare impacts an individual's ability to receive an organ donation and/or undergo a transplant procedure. The committees request that the Maryland Health Care Commission (MHCC) submit a report that reviews the existing policies governing the eligibility for receiving an organ donation, identifies reasons for denial of organ transplantation, and the number of individuals who had organ transplant needs denied or deferred under each reason since calendar 2018. This report should specifically consider the financial requirements that may be a cause of the denial or deferral of care in the State. Information Request Report on hospital policies limiting to organ transplant eligibility.

Information Request: Report on hospital policies limiting to organ transplant eligibility

Author: MHCC

Due Date: October 1, 2022





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