

Psychosocial Aspects of Liver Transplantation for Metabolic Conditions:

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Considering liver transplantation for the treatment of a metabolic condition is a significant step. We understand that it required a lot of deliberation to arrive at the decision to explore transplantation as a treatment option. We also understand that there are many factors to consider in making such a decision and that the psychosocial aspects of living with a metabolic condition, undergoing liver transplantation, and thereafter living with a liver transplant can be a significant component in decision making. As such we wanted to provide patients and caregivers with a brief guide regarding the psychosocial factors and risks that may be part of the transplant process.

Psychosocial Factors to Consider:

Patients with metabolic conditions can experience a variety of challenges in association with their underlying condition. The more common conditions for which we offer liver transplantation, [Maple Syrup Urine Disease \(MSUD\)](#), [Methylmalonic Acidemia \(MMA\)](#), [Propionic Acidemia \(PA\)](#), and [Urea Cycle Defect \(UCD\)](#) are associated with various developmental, cognitive, academic, dietary, quality of life, and psychological concerns. The level to which each of these concerns evidence themselves depends upon a variety of factors including the severity/subtype of the presenting condition, the number and severity of pre-existing metabolic crises prior to transplant, hyperammonemia episodes, presence of seizure disorders, and metabolic acidosis. Below are brief summaries of the areas that have been observed, researched, and/or documented to be affected.

Developmental Delay:

Developmental delays can include growth retardation, slow and/or lack of attainment of developmental milestones (e.g., walking, talking), feeding delay and/or oral motor delay, oral aversion, and/or cognitive delay. Delays can manifest themselves early in the developmental trajectory or evolve after metabolic crises. Fine and gross motor functioning as well as social and cognitive functioning can be impacted.

Academic and Executive Functioning Concerns:

Learning disabilities and/or delays are common among patients with an underlying metabolic condition. Clinical presentations vary and can include math learning disabilities,

reading disabilities, attention and memory concerns, and organizational difficulties. Patients who have experienced significant metabolic crises may evidence a wide range of academic concerns that require special education support.

Dietary:

Due to the common dietary restrictions in patients with metabolic conditions many patients develop feeding intolerance, oral/motor delays, and/or oral aversions. These presentations vary in the underlying mechanism being affected. For example, some patients have difficulty with the mechanics of chewing and/or swallowing, while others have difficulties adjusting to the various textures of food. Following transplantation patients may continue to have challenges in these areas and may require treatment and support to be able to accept a new expanded diet.

Quality of Life:

Patients with metabolic conditions often have lifestyle restrictions such as dietary and activity restrictions, and physical limitations that may be associated with their condition. In addition, given that a metabolic crisis may develop unexpectedly patients can also experience increased stress and difficulties adjusting to their diagnosis and associated medical needs.

Psychological Concerns:

Mood disorders, attention disorders, and behavioral disorders are generally common among patients with metabolic conditions. Anxiety, depression, and bipolar disorder have been well documented. Similarly, Attention Deficit Hyperactivity Disorder and/or subclinical types of this diagnosis are common within these patient populations. Further, adjustment to a lifelong chronic illness and the associated treatment can cause emotional strain and exacerbate psychological conditions.

Potential Psychosocial Supports:

Given the range of concerns that may be present in patients with metabolic conditions it is important to consider the following services that could assist in improving and/or decreasing the impact of the condition. Below is a list of potential resources and how they may be of assistance.

Transplant Psychology:

The Transplant Psychology Service is also available to provide support to patients and families exploring the possibility of liver transplantation for an underlying metabolic condition and for those going through the liver transplant process. This service is there to

support patients and families as they navigate getting ready for transplant, undergo transplant, and move through the post-transplant process.

[Early Intervention and Support Therapies:](#)

Early Intervention services are often recommended for patients with metabolic conditions. These services can help evaluate the developmental level of the patient and make recommendations regarding physical, occupational, speech and feeding therapies. These services are a great resource as they can help the patient reach developmental milestones and decrease the developmental impact of the condition. Your local pediatrician can help make a referral to these services.

[School-based Services:](#)

Patients with metabolic conditions can often benefit from assistance at school. Patients who have been identified with a disability have access to a 504 Plan. A 504 Plan is a US federally funded plan that assures that patients with a disability can receive accommodations at school to promote their success. Patients who are diagnosed with a learning disability, learning delay and/or cognitive delay can also request an Individualized Educational Plan (IEP). An IEP allows patients to receive a psychoeducational evaluation within the school system to assess their strengths and areas in need of support. An IEP can then provide the patient, his/her family, and educators with an academic plan with goals and strategies that promote the patient's academic success. If you suspect or believe your child can benefit from such a plan contacting your school is the first step to putting a plan in place.

[Mental Health Evaluation and Support:](#)

Similar to the testing that patients can receive within the school system, a neuropsychological evaluation is often recommended for patients with metabolic conditions. Neuropsychological testing examines how a person's brain functions affect their behaviors. This type of testing helps pinpoint areas of strength and areas in need of support. A neuropsychological evaluation provides a more in-depth understanding of the patient's cognitive functioning and provides a thorough understanding of memory, attention, and executive functioning abilities (the abilities that help us order and put our thoughts/behaviors together). Such an assessment can provide significant insight into areas that may need additional support. For example, some children with metabolic conditions find it difficult to organize information and show consistent focus when doing schoolwork. A neuropsychological evaluation can help pinpoint whether these difficulties are related to attention, focus, memory function, or some other potential challenge. If you believe there would be benefit from this type of evaluation, you can ask your child's physician to refer for evaluation or self-refer depending on insurance requirements.

In addition to the above and given the increased likelihood of mood disorders in patients with metabolic conditions, psychological assessment and potential mental health treatment may be of help. Further, because patients who undergo liver transplantation can experience some emotional challenges as part of their response to transplantation and subsequent treatment, psychotherapy that focuses on coping with a chronic medical condition and/or psychotropic medication management (e.g., medications for anxiety/depression) may be a good option for a number of patients.

Conclusions and Recommendations:

Patients with metabolic conditions have a great opportunity for stabilization and potential improvement following liver transplantation. The above are areas that can help improve the overall outcomes for patients. The information is only a brief review and not meant to be exhaustive. Your team is there to support you as you go through this process and to provide you with resources and recommendations as needed.