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## A Little Digital Help: Advancing Social Support for Transplant Patients with Technology

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Berry, Daniels, and Ladin (2019) question the relevance and acceptability of using social support evaluations as criterion for listing patients as candidates for an organ transplant. Even if research demonstrates low social support predicts poor transplant outcomes, Berry, Daniels, and Ladin (2019) argue that all patients should be screened for social support and offered assistance, rather than being excluded from transplant listing for lack of social support. We wish to expand upon Berry, Daniels, and Ladin (2019) recommendations by describing in greater detail digital technology-based innovations in transplant medicine that could improve post-transplant outcomes for patients, especially those needing extra social support. We aim to provide concrete next steps for providers, researchers and hospital administrators to attain the broad goals outlined by Berry, Daniels, and Ladin (2019). Doing so could not only improve outcomes for patients in need of social support, but could also improve disparities in transplant outcomes by contributing to greater health equity.

Though transplant centers evaluate and weigh social support differently when placing patients on the transplant list, patients are often asked to demonstrate that they have at least one person who can provide caretaking during the post-transplant recovery (Berry, Daniels, and Ladin (2019)). This support is often expected to be instrumental, informational, and emotional (Berry, Daniels, and Ladin (2019)). While all are important, we focus in this article on instrumental support and its relevance to adhering to post-transplant regimen (e.g., immunosuppression medication adherence), a critical factor for post-transplant recovery (Fleming et al. 2017). Exploring alternative ways to provide instrumental support to maximize adherence for patients with low or no social support could improve outcomes for these populations.

mHealth (mobile health) interventions in transplant medicine show promise in aiding in patients' post-operative care, and are feasible, desired by patients, and often cost-effective (Fleming et al. 2017). Recently, Geramita et al. (2019) conducted a randomized controlled trial of an mHealth intervention, Pocket PATH, to promote self-care management for lung transplant patients. The Pocket PATH app was designed to help patients remember to take their medications, report and monitor symptoms, and assist with decision making about when to seek further help from their care team (Geramita et al. 2019). In the short-term (12 months), use of the Pocket PATH app resulted in reduced medication nonadherence compared to the standard of care group; however, at long-term follow up of approximately 4 years most differences in nonadherence disappeared (Geramita et al. 2019).

The Pocket PATH study shows us that mHealth interventions can improve short-term medication adherence, but cautions that these may not translate into long-term improvement without additional modifications to increase patient engagement (Saha and Henderson 2019; Geramita et al. 2019). The short-term effectiveness of mHealth interventions suggests that patients who need close post-transplant monitoring may be best suited to these interventions, such as recipients living with Hepatitis C undergoing additional treatment, or adolescents at key transition points (e.g., moving out of their parents' home) (Saha and Henderson 2019).

Another example of a mHealth intervention in transplant medicine is the mKidney system, currently being evaluated for its ability to assist with required follow-up care management for living kidney donors, which has historically proven difficult for both transplant centers and living donors (Henderson et al. 2019). mKidney sends reminders about completing follow-up tasks, enables patients to fill out questionnaires within the app, and allows the transplant team to monitor submitted data (Henderson et al. 2019). In this way, mHealth interventions can also aid providers in monitoring patients post-operatively. On the horizon is the use of artificial intelligence (AI) and smart speakers (e.g., Alexa, Siri) to assist with post-transplant medication adherence. AI can provide insights to augment clinical practice and decision-making, potentially reduce diagnostic and therapeutic errors, and extract useful information from large patient populations to assist with real-time inferences for health risk alerts and outcome prediction (Dilsizian and Siegel 2014).

Other innovations are attempting to harness social media to improve transplant outcomes and adherence. As an example, Liver Space and Kidney Space are Facebook-integrated health applications developed at Johns Hopkins which provide reliable information and a place for patients to connect with others about transplantation (Mogul, Henderson, and Bridges 2018). Unlike other similar sites or Facebook pages or groups, health professionals vet all posted content and respond on public forums and to private messages (Mogul, Henderson, and Bridges 2018). Patients are able to track their weight and other lab values directly within the application (Mogul, Henderson, and Bridges 2018). Social media interventions offer the potential for patients to receive informational (e.g., accessing key educational information), instrumental (e.g., receiving reminders, contacting experts) and emotional support (e.g., connecting with other patients) on one platform.

In addition to improving post-transplant adherence and engagement for patients, mHealth and social media interventions could also aid transplant centers in implementing recommendations to “gather data to analyze transplant outcomes among weakly supported patients, which will be used to inform the care and listing policy for future patients” (Berry, Daniels, and Ladin (2019), pp). mHealth tools can provide clinically actionable information for providers about individual patients (e.g., mobile directly observed therapy (mDOT) where patients record videos of themselves taking their medications to help track their adherence, recovery, and symptoms) and offer the possibility of a rich dataset for hospitals to track aggregate outcomes. In this sense, mHealth data offers dual utility: the ability to improve patient outcomes and assist hospital administration with tracking and reporting outcomes.

Data from mHealth interventions could also help transplant hospitals identify risk factors for unfavorable outcomes post-transplant. Rather than exclude higher risk patients from being listed, this information should be used to flag patients that may need extra support before and after their transplant (Maldonado et al. 2012). For example, if patients with low instrumental support are found to have more challenging recoveries, transplant hospitals should screen patients for low instrumental support pre-transplant, and prioritize these patients for mHealth interventions and other resources that demonstrate effectiveness in increasing instrumental social support. In other words, post-transplant data collected with mHealth can inform pre-transplant care for other patients.

In order to reliably identify patients with low social support for possible intervention, it is critical to implement evidence-based, objective measures to evaluate social support. Listing practices and the conduct of psychosocial evaluations vary by U.S. hospital, which in turn impacts patients' ability to be placed on the transplant list (Maldonado et al. 2012; Berry, Daniels, and Ladin (2019)). The Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) is a measure that operationalizes social support in a way that allows for objective evaluation (Maldonado et al. 2012); using measures like the SIPAT could help to eliminate bias in listing practices (Berry, Daniels, and Ladin (2019)). Use of such a measure could help to parse which psychosocial domains impact outcomes and which do not, ultimately helping to identify patients who are prime candidates for digital support.

While mHealth data provides a valuable opportunity to identify patient-level characteristics that may increase the likelihood of nonadherence, interventions should also be informed and refined based on users' input. Patients' reasons for immunosuppression medication nonadherence may vary—complicated medication regimes can be difficult to follow, it may be hard to remember to take medications on time, and side-effects can be unpleasant (Dew et al. 2018). Mobile app developers could tailor features to appropriately address barriers specific to the user. Patient feedback during and after development can help to identify which features are most effective and preferred, and which areas require improvement.

Finally, mHealth could contribute both to reducing disparities in listing and achieving greater health equity in post-transplant outcomes. Rather than using low social support as an exclusion criterion for listing, alternative ways to provide support should be explored to achieve greater listing equity (Berry, Daniels, and Ladin (2019)). We described recent and ongoing innovative mHealth interventions that can provide instrumental support to patients in need. Similar interventions could also help to narrow disparities in post-transplant outcomes between groups. For example, kidney transplant patients who live far from transplant centers have a higher chance of post-transplant mortality than those who live closer, even when controlling for demographic and clinical characteristics (Axelrod et al. 2010). mHealth interventions that allow for remote monitoring of symptoms and easy online contact with providers may help to decrease geographic disparities in outcomes. Similarly, mobile apps could also integrate medication reminders and care team linkage from multiple departments for patients with comorbid conditions, who may otherwise have worse outcomes. mHealth data can help to identify other factors that influence post-operative recovery to inform future interventions to achieve greater health equity in transplant outcomes.

Digital technologies could play a major role in helping patients in need of social support and, more broadly, aiding in all patients' post-operative recovery, particularly for groups at higher risk of adverse outcomes after transplantation. We recommend the continued evaluation of digital health technologies to expand the options for advancing social support in transplant patient populations.

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