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Research in the Works

Into the Light: Using Technology to Develop a Mother/Family Centered Peer Support Network

Shannon Hennig, Katherine Stone, and Joanne Nicholson

Perinatal mood and anxiety disorders (PMADs) are estimated to occur in up to 20% of women who are either pregnant or have recently given birth and can include postpartum depression, anxiety, obsessive compulsive disorder, mania and psychosis.^{1,2} Of women diagnosed with a PMAD only a small number will receive treatment.³ For some women the stigma and shame associated with mental illness prevent their help seeking, and access to care may be limited by time and resource constraints. The prevalence and limited treatment of these illnesses make PMADs a significant public health issue. Left untreated, these illnesses can dramatically impact a woman's ability to care for herself and her child, and in severe cases may result in maternal and/or infant mortality. Peer support has been demonstrated as an effective treatment intervention when delivered in-person and over the phone.^{1,3,4,5} However with the increasing popularity of online patient communities and social media in health care delivery, further exploration of peer support delivered through online and mobile technology is needed. The use of technology has the potential to dramatically improve access to peer support and ultimately to treatment for women from underserved communities and those in rural locations.

Into the Light is a Tier 1 Patient Centered Research Outcomes Institute (PCORI) Pipeline to Proposal project. Postpartum Progress Inc. (PPI), the lead organization, is a national non-profit dedicated to raising awareness and reducing stigma related to maternal mental illness. The project team, comprised of five patients with lived experience, a project lead and a research lead, will identify key stakeholders, and build collaborative relationships with the academic community to develop

comparative effectiveness research based questions regarding women with perinatal mental health conditions. Central to the project is the development of patient engagement and recruitment strategies, and a dissemination plan that translates outcomes into accessible, easy to understand information to assist patients in making health related decisions.

PPI is an innovative leader in the development of online peer support networks and has successfully built an online community of women across the US and around the world via online communication tools and social media. (Visit www.postpartumprogress.org.) The PPI blog, founded in 2004, is the most widely read blog in the world on perinatal mental illnesses (over 3 million page views to date in 2016). The PPI Facebook page has over 32,000 followers. PPI provides a monitored, private web-based peer support forum (involving over 6,000 mothers); a closed Facebook group (with over 125 participants); international distribution of free patient- focused education tools; the world's largest annual event raising awareness of maternal mental illness; and an annual patient-focused conference.

Over the next months, the Into the Light team will: (1) develop better ways to understand the efficacy of peer support; (2) explore peer support models enabled by health technology, to augment clinical treatment (medication and/or psychotherapy) and to explore additional options for women and their families; and (3) specify engagement, recruitment and dissemination strategies for women with perinatal mental health conditions to facilitate their participation in future research. The ultimate goal is to generate patient-informed research questions with real-world relevance and impact.

Into the Light is a capacity building initiative led by Postpartum Progress Inc. (Shannon Hennig, MA) with five patient leaders (Sara Beckel, Cindy Lee-Herrick, Graeme Seabrook, Chelsea Steiner, and Lisa Tremayne) in collaboration with The Geisel School of Medicine at Dartmouth (Joanne Nicholson, PhD). This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Pipeline-to-Proposal Award #5134284, administered on behalf of PCORI by the National Network of Public Health Institutes.

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