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MEW Network Self-Management Program Characteristics and Lessons Learned through the RE-AIM Framework

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Abstract

Rationale: The promotion of evidence-based self-management support for people living with chronic conditions such as epilepsy is a public health priority. Epilepsy self-management encompasses three general areas: 1) treatment management, 2) seizure management, and 3) lifestyle management. Interventions focusing on self-management have increased quality of life and adherence to treatment. ***This study assesses and synthesizes*** the Managing Epilepsy Well Network (MEWN) program implementation experiences using the RE-AIM framework. This research informs the quality and rigor of MEWN program dissemination and implementation efforts to assess whether these programs are being implemented and their scalability.

Methods: The study data were derived from a MEWN Self-management Program Survey conducted with currently active MEWN researchers through an online survey and review of program publications and archival documents. Survey data were obtained from either the principal investigator or study team for the UPLIFT, HOBSCOTCH, SMART, MINDSET, TIME, and PACES programs. The survey questionnaire included 6 sections consisting of 68 questions and

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Declaration of competing interest

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focused on the RE-AIM dimensions and respondent characteristics. The RE-AIM dimensions included: 1) Reach, 2) Effectiveness, 3) Adoption (number of and type of adopting sites), 4) Implementation (retention rate, barriers to implementation), and 5) Maintenance.

Results: Across the MEWN programs, participation (44–120 individuals) and delivery methods (community, clinic, or asynchronous; group or individual) ranged with most programs predominantly reaching White or African American participants. Common program outcome measures included clinical outcomes (e.g., depression, quality of life, seizure frequency) and indicators of self-management behaviors (e.g., problem-solving; self-efficacy). Initial efficacy trials suggested programs were effective in changing some of their targeted outcomes (effectiveness). Most programs were implemented in clinical settings and several programs are being replicated or adapted to different geographical (e.g., urban, rural, suburban) or demographic (e.g., race, age) settings (adoption). Program delivery methods involved a mixture of program staff, peer educators, and researchers. Implementation enabling factors included partnerships with local epilepsy organizations and inclusion of peer educators. Retention rates for all programs averaged to 83.6%. Internal barriers included recruitment and lack of sufficient resources for participants. External barriers included clinical staff buy-in, staffing, and insufficient funding for support staff. Despite uncertain funding, all programs offered next steps to sustain their initiatives such as packaging their programs, initiating adoption with regional organizations, and supporting organizational readiness (maintenance). Dissemination efforts included partnering with other organizations, provision of training and technical assistance and partnering with national organizations on grant opportunities to scale-up existing programs.

Conclusion: These data showcase the impact of the MEWN self-management interventions on health and quality of life. These programs are employing training, readiness assessment, technical assistance, and development of partnerships to increase program scalability. Finally, program adaptations are being conducted to expand the interventions to other populations to address health inequalities. The lessons learned are critical for other interventions attempting to increase translation of their programs to other settings.

1. INTRODUCTION

Promoting evidence-based self-management support for people living with chronic conditions such as epilepsy is a public health priority [1, 2]. In contrast with arthritis, asthma, diabetes, and other conditions for which there are standardized protocols and referral mechanisms, credentialed provider training programs, funding, and community-based partners engaged in self-management program delivery [3–5], the infrastructure for epilepsy self-management support is emerging. For the almost 3 million adults living with epilepsy, self-management encompasses three general areas: 1) treatment management, 2) seizure management, and 3) lifestyle management [6, 7]. As described elsewhere, the U.S. Centers for Disease Control and Prevention (CDC) has supported research on epilepsy self-management program development, dissemination, and implementation in response to consensus recommendations from national stakeholders (e.g., Living Well with Epilepsy II (2003)) [8]. By 2007, CDC established the Managing Epilepsy Well Network (MEWN) as one of its Prevention Research Centers Program thematic networks [9, 10].

The aim of the MEWN is to improve the health and well-being of people with epilepsy (PWE) by advancing epilepsy self-management research, evaluation, and program dissemination. The MEWN is currently comprised of a Coordinating Center (Emory University and Dartmouth College) and four collaborating Centers including New York University, University of Iowa, University of Washington, and University of Arizona net [11]. Members work with national and regional partners including the American Epilepsy Society, Epilepsy Foundation, Epilepsy Alliance, and other local entities to fulfill its mission. Since its inception, MEWN investigators developed 8 evidence-based programs: HOBSCOTCH, MINDSET (English and Spanish versions), PACES, PEARLS for Epilepsy, SMART, TIME, UPLIFT (English and Spanish versions), and WebEase, with others in different phases of assessment [12–18]. The MEWN has provided national leadership in conducting trainings for multidisciplinary providers on epilepsy self-management and MEWN program protocols to foster delivery of these programs in local communities to reach more people with epilepsy and enhance their quality of life.

Despite the growth in the number of proven and promising MEWN programs cited in recent systematic reviews, less is known about the quality and rigor of MEWN program dissemination and implementation strategies to assess whether these programs are being implemented and used as intended [19, 20]. Therefore, as part of the 2019–2024 funding cycle, the MEWN is examining intervention implementation factors.

Many dissemination models for public health programs exist [21]. The Translational Pipeline describes the development and dissemination of programs along time and generalizability axes (Figure 1) [22]. This Pipeline model was adopted for this study to describe the development and dissemination of MEW Network programs. The dissemination and implementation phase of this model describes four phases: *Exploration* (identifying if program implementers find a program useful in their local context); *Preparation* (establishing new collaborations and processes needed for implementation of the program (i.e., what modifications to current system are necessary to implement the new program)); *Implementation* (supporting delivery in a manner that maintains fidelity); and *Sustainment* (supporting implementers in maintaining their progams). Several frameworks exist to guide evaluation of program implementation across these four phases. This study focuses on an application of the Reach, Efficacy, Adoption, Implementation, and Maintenance (RE-AIM) framework [23].

RE-AIM is an implementation framework to evaluate how evidence-based programs or interventions (EBIs) are disseminated and implemented with an emphasis on external validity across several quality dimensions: *Reach* (the number or proportion of people willing to participate in a program or intervention, and to what populations those willing participants generalize); *Effectiveness* (how a program contributes to changes in outcomes); *Adoption* (the number or proportion of settings and implementers who are willing to initiate a program or intervention, and to what characteristics those settings/implementers can generalize—importantly, this dimension is often reported at the setting level and staffing level); *Implementation* (the fidelity with which a program or intervention is delivered, how the program is delivered and examination of implementation facilitators and barriers); and

Maintenance (the degree to which a program or intervention becomes part of the routine/operation of an organization or setting) [23, 24].

The RE-AIM framework can be used to compare programs across dimensions of focus, yielding information as to whether and why programs successfully move from an efficacy or pilot setting into applied conditions. Previous work has utilized RE-AIM in evaluation settings for a variety of chronic diseases or risk factors for chronic diseases (e.g., obesity, poor physical activity) as well as self-management programs [25–28]. To our knowledge, this is the first effort to apply the RE-AIM framework to assess program implementation characteristics of epilepsy-specific self-management programs. The purpose of this study is to assess and synthesize MEW Network program implementation experiences using the RE-AIM framework. These data may inform ways to increase and enhance MEWN program implementation in more U.S. communities, and the development and scalability of other intervention programs for people with epilepsy.

2.0 METHODS

The purpose of this analysis was to focus on efficacy data from six active epilepsy self-management programs. The study data were derived from a MEWN Self-management Program Survey conducted with currently active MEWN researchers through Survey Monkey, and from MEWN self-management program publications, and archival documents. The study survey was developed from researchers from Emory who included epilepsy researchers and an implementation scientist. RE-AIM questions were derived from its website (re-aim.org) and an article about the model [26]. Because this evaluation study was not considered human subjects research, the Emory IRB deemed this study as non-research.

2.1 Target Population

The survey was distributed in Spring 2021 to either the principal investigator and/or the program coordinator (implementation leads) for the UPLIFT, HOBSCOTCH, SMART, MINDSET, TIME and PACES programs. These programs were selected because they were developed in previous MEWN funding cycles (2004–2009; 2014–2019) and are supported within the 2019–2024 funding period. Only one person from each program took the survey. The participants were asked to provide publications in order to describe their program in further detail.

2.2 Survey Development and RE-AIM Operationalization

The five RE-AIM dimensions were operationalized within the survey with sets of questions that assessed the following dimensions: 1) *Reach*--the overall number of participants, demographics of participants, and general setting (e.g., rural vs. urban); 2) *Effectiveness*--the extent to which a program impacted its stated goals (e.g., effectiveness of improving quality of life or reducing depressive symptoms in treatment vs. control conditions); 3) *Adoption*--the number of and type of sites that had implemented a given program; 4) *Implementation*—the retention rate, feasibility of recruiting participants into programs, and barriers and facilitators to program implementation; and 5) M*aintenance*--the willingness of respondents to offer the program again and action steps to replicate or expand a given program [29].

The final survey included 6 sections consisting of 68 questions focused on the RE-AIM dimensions and respondent characteristics. The respondent characteristics section included questions about the organization and decisions to implement the program such as, "How would you describe your organization?" and "What made you/the organization decide to introduce your program to the organization?" In this case, the organization is an agency who wants to adopt the MEWN program. Examples of questions within the *reach* domain included, "How many people were recruited for your program?" and "Did you experience barriers that affected program recruitment?" The *effectiveness* domain included questions such as, "What were some indicators of success for the program for you/your organization?" and "What were some aspects of the program you thought were not effective, if any?" Questions in the *adoption* domain included, "How representative were the other organizations that participated in the program?" and "What were the perceived disadvantages of delivering the program at your organization, if any?" The *implementation* domain contained questions about program delivery such as, "Who delivered your program?" and "What are barriers to implementing the program?" Finally, the *maintenance* domain included questions related to program sustainability such as, "Have you continued to offer your program within your organization?" and "Has your organization or program staff taken any steps in sustaining the program?" On average, the survey took 45 minutes to complete. From the publications of the MEWN programs, we abstracted data on participant demograhics, key outcome measures, key findings and retention of partipants.

2.3 Data Analysis

The study team reviewed qualitative and quantitative information and synthesized data in alignment with the RE-AIM framework. Demographic characteristics of MEWN program participants were analyzed with descriptive statistics using SPSS version 26.0. Qualitative data were compiled from survey into tables to identify themes, and data were summarized further or condensed for clarity. We included the range of qualitative responses from the short answer survey questions in tables (i.e., barriers) and then we conducted thematic analyses of the common factors (i.e., facilators to implementation) through review by two coders [30]. The study team validated the data in the tables through cross referencing with corresponding publications and the program developers reviewed data foreach program.

3 RESULTS

Although the MEWN program intervention components are detailed elsewhere [12–16, 18], the approximate timeframe on each selected program's development, implementation, and dissemination, are provided in Figure 2 and an overview of program key components are summarized (Table 1).

We synthesized key metrics from survey responses, existing publications, and reflections from program staff/researchers ("respondents") of the six epilepsy self-management programs through their research implementation and organization along dimensions of the RE-AIM framework from survey responses. The respondents included 6 people who were either program developers (n=2, one developed 2 programs), and coordinators or trainers (n=3).

3.1 Reach

The MEWN self-management programs had a range of participation, delivery methods and study designs. Across the programs, the participation ranged from 44 to 120 adults for the first efficacy trial for each program, with a mean age range of 35.9 – 48.25. A variety of delivery settings were represented, including medical clinics (HOBSCOTCH, PACES, MINDSET), community settings (TIME), or at home/asynchronous (UPLIFT, SMART) and with both individual (HOBSCOTCH, MINDSET) and group (PACES, TIME, SMART, UPLIFT) formats. Whites and African Americans (AA) were most represented throughout the six programs (Table 2). Some programs reached a majority of AA participants (SMART, TIME). Participation among whites ranged from 30.1% (SMART) to 89% (PACES). Participation among AA ranged from 6% (PACES) to 69.9% (SMART). Those with Hispanic ethnicity had lower participation relative to whites and AA. Most of the programs had either no Hispanic participants (UPLIFT) or a small proportion of 6–7% (SMART, PACES, TIME). One program focused solely on Hispanic participation (100%, MINDSET). The two most common recruitment strategies were clinic-based recruitment and word of mouth. Other recruitment strategies included print and electronic advertisement, organization website, and recruitment through partner organizations. The facilitators were community members with epilepsy (HOBSCOTCH, SMART, PACES, TIME), healthcare staff (UPLIFT, HOBSCOTCH, SMART, MINDSET, PACES, TIME), and/or research staff (UPLIFT, HOBSCOTCH, MINDSET, PACES). With respect to geography, all but one of the programs recruited in an urban or suburban setting. One program (HOBSCOTCH) drew initially from a rural patient base. In addition, the SMART program is currently being implemented in rural settings and an initial feasibility study for rural settings was done with the PACES program (Table 2) [31, 32].

3.2 Effectiveness

The most common outcome measures across the six programs included clinical outcomes and indicators of epilepsy self-management behaviors. Two common measures included depression (UPLIFT, SMART, PACES, TIME), and quality of life (QOL) (UPLIFT, PACES, HOBSCOTCH, SMART), subsequently followed by metrics around epilepsy complications and seizure frequency (SMART, UPLIFT), and cognitive dysfunction (HOBSCOTCH). Self-management measures included epilepsy self-efficacy (PACES), health knowledge/skills (UPLIFT), self-management program adherence (MINDSET, PACES), and compensatory strategies and problem-solving therapy (HOBSCOTCH) (Table 2).

Efficacy trials for all six programs indicate that each program was effective in changing some dimensions of targeted outcomes. For example, all four studies which measured QOL demonstrated some type of improvement in QOL among participants, with two out of the four reporting significant differences between treatment and control (SMART, PACES) [14, 15]. Similarly, all studies which measured depression suggested program participation contributed to reduced depression severity, with three out of the four programs reporting significant differences between treatment and control arms (UPLIFT, SMART, TIME) [13, 15, 16]. Additionally, participation in UPLIFT and SMART showed a reduction in seizure frequency in PWE [15, 33] (Table 2).

Each program had indicators of success and varied by programs. Examples of indicators of success include improvement in depressive symptoms, program or participant satisfaction, program retention rates, and increase in program awareness and delivery (Table 2).

3.3 Adoption

Program adopters (agencies wanting to adopt the MEWN programs) were based in healthcare or clinical settings in the efficacy trials ("initial phase"). Programs earlier in development and dissemination phase (PACES, TIME, and UPLIFT) had been implemented at a single clinic or site (Table 3). Others were implemented at multiple sites in their initial phase (HOBSCOTCH, SMART, MINDSET). UPLIFT for Prevention was implemented in multiple sites in an NIH-funded replication study.

Replication sites (settings where MEWN programs were adopted) included different clinical groups within the same development institution (HOBSCOTCH), as these institutions received funding to conduct replication studies (Table 4). For example, PACES has been replicated with patients drawn from urban and rural community-based epilepsy centers, and has been adapted for telephone delivery [34]. HOBSCOTCH has been replicated several times with the original development institution (place where MEWN program was first developed) and is currently undergoing replication in sites with greater diversity than was present in the original development location [35, 36]. MINDSET is also being replicated at its original site and also in a broader clinical population beyond the initial Hispanic demographic focus. Efforts remain underway with the original program development institution to explore replication opportunities (Table 4).

Some self-management programs are being adapted for different settings or populations. Adaptations have been made to the UPLIFT program for AA adults, and UPLIFT, HOBSCOTCH and PACES have been or are being adapted for Spanish speaking populations (Table 4) [37–39]. The PACES and HOBSCOTCH programs are being adapted for adolescents. Key elements of the in-person TIME program were adapted to create the virtually delivered SMART program and SMART has been adapted to a fully virtual format in conjunction with epilepsy-focused social services agencies [40]. MINDSET has been adapted for multiple digital platforms including desktop, tablet, and smartphone.

3.4 Implementation

A mixture of delivery methods was represented, including phone or virtual delivery (e.g., video-conference calling, web-based) (UPLIFT, PACES, SMART), in-person (MINDSET, PACES, TIME, SMART), or a mixture (HOBSCOTCH) (Table 1). All applicable program implementation (except MINDSET) consisted of at least 8 sessions (45–90 minutes per session). Sessions were either entirely individual (HOBSCOTCH), entirely group based (PACES, UPLIFT), or a mixture of both (TIME, SMART). Groups ranged from 5–10 participants. All self-management programs were led by a trained dyad comprised of an epilepsy professional and a trained peer with the disability. One program included a peer education component, with additional training unique to a person with epilepsy acting as program delivery staff (PACES, UPLIFT, SMART). Most of the programs also considered researchers as part of the implementation staff (UPLIFT, HOBSCOTCH, MINDSET,

PACES). Lastly, HOBSCOTCH included a trained memory coach for program delivery in addition to healthcare and research staff who facilitated referral and administrative tasks. Participant retention rates across the 6 programs ranged from 73%−97%. Several programs had a retention rate of greater than 70% for at least one program implementation (UPLIFT, HOBSCOTCH, MINDSET, PACES, TIME) (Table 3).

Implementation Enabling Factors—Survey respondents identified/described several enabling factors to facilitate implementation of their programs. The most common factors were establishing partnerships with epilepsy-focused social service agencies (e.g., local Epilepsy Foundation chapter; regional epilepsy association) or community mental health centers (TIME), having sessions co-facilitated by PWE or epilepsy professional (UPLIFT, HOBSCOTCH, PACES, MINDSET), and multiple recruitment/outreach approaches such as letters or web-based advertisement (HOBSCOTCH, SMART) or medical record query in clinical settings (SMART).

Implementation Barriers—Overall, respondents identified participant recruitment and retention as major barriers. Some reported no barriers (HOBSCOTCH, PACES). Others reported barriers including participants missing clinical appointments with program components, insufficient resources for number of eligible participants, or general recruitment challenges and delays (Table 3).

There were issues reported with regard to program delivery at adopting organizations. Barriers with the implementation staff included timing/scheduling/staffing limitations (UPLIFT, PACES, MINDSET, TIME), adequate compensation for implementation/research staff (UPLIFT, HOBSCOTCH, PACES, TIME), and issues with program software (MINDSET) (Table 3). Additional themes came up in reference to future dissemination such as lack of staff buy-in, low perceived value of a given program, and inability to bill by clinical practitioners/institutions at implementation sites due to only some staff attending the formal program training (UPLIFT, PACES).

Lessons Learned—Respondents described anticipated funding loss precluding sustaining program delivery beyond designated funding periods or funding parameters. For instance, having sufficient resources allowed some programs to train new facilitators (UPLIFT) while perceived lack of resources precluded expansion of delivery to additional medical center sites (PACES). Other lessons described focused on the need for enhanced training and technical assistance capacity for interested community-based program adopters, technical logistics (e.g., internet access and challenges with online group coordination), and participant recruitment and session scheduling challenges (Table 4).

3.5 Maintenance & Dissemination

For a given program, there were mixed responses on whether a self-management program would be offered beyond the funding period (2019–2024). Several programs have undergone or are undergoing replication (HOBSCOTCH, UPLIFT, SMART, MINDSET), or effectiveness research (PACES), or have been or are currently adapting to additional populations (PACES, HOBSCOTCH, UPLIFT, TIME) (Table 3). Despite the mixed

responses on prospects of offering programs again relative to uncertain funding, all sites provided next steps which staff were taking to move forward which included: identifying barriers/facilitators to initial implementation, searching for additional funding, considering different implementation format (virtual vs. in-person), and working to initiate adoption and sustain programs with regional organizations (Table 4). Three programs have developed readiness checklist tools to help interested organizations to assess if they have the resources necessary to implement the program (UPLIFT, HOBSCOTCH, and PACES).

Some dissemination efforts of a given program included partnering with regional or local epilepsy-focused organizations, EF affiliates, or additional clinical sites (UPLIFT, SMART, PACES, HOBSCOTCH). One program (UPLIFT) also incorporated an educational initiative to train program delivery staff. HOBSCOTCH and PACES are offering training to providers and practitioners to implement their program. National partners also are key to program dissemination. With CDC funding, the Epilepsy Foundation has offered mini-grants for programs to offer select MEWN programs since 2013 (e.g., UPLIFT, HOBSCOTCH, PACES). Additionally, the Epilepsy Association/Alliance received funding in 2021 from the CDC to scale-up SMART in the northeastern/mid-western U.S (Table 4).

4. DISCUSSSION

This paper is the first to summarize the research setting implementation efforts of six epilepsy self-management programs using the RE-AIM framework. The MEWN programs demonstrate feasibility for implementation in urban or suburban settings, reaching white and AA PWE and with virtual delivery. For PWE, distance-based programs are critical for increasing reach since many individuals cannot drive or may have transportation barriers. Collectively, this demonstrates that the MEWN programs appeal to different racial/ethnic groups to ensure health equity. The MEWN programs may have to expand promotion of the programs to reach more rural regions and to work with organizations serving diverse PWE to increase the reach to other minority populations. Several systematic reviews of self-management and psychosocial programs for PWE have found mixed modes of delivery like the MEWN programs; those programs focused mainly on knowledge acquisition, problem solving and self-management (e.g., medication, symptom tracking, safety) [41]. The MEWN programs generally were effective at improving selected outcomes, notably QOL and depressive symptoms with promising findings on seizure reduction in a few of the programs. Other reviews of self-management for psychosocial interventions for PWE have found some limited evidence of their impacts on depression, quality of life, and other self-management outcomes [19, 20, 41]. These findings show the impact on reducing depression among our MEWN programs.

Implementation enabling factors included having epilepsy providers serve as session facilitators, training peers with epilepsy, and partnering with epilepsy social service agencies for referrals or intervention delivery. Overall, five MEWN programs had high retention rates of participants of 80% or higher. This finding is in contrast to research on other self-management programs that have experienced much higher attrition rates [42]. The MEWN programs' retention success could be due to program appeal for PWE, program incentives, sense of community and social support offered and participant motivation for

improved health. In addition, all were designed with patient and stakeholder input, shown to increase program engagement [43]. Our study is the first to highlight key facilitators to implementing self-management programs for PWE.

In our study, the reported barriers to implementation for epilepsy self-management programs included recruitment challenges (e.g., insufficient resources, program delays) and actual program delivery (e.g., staffing, funding, lack of buy-in among staff); these finding are similar to those reported in other published epilepsy SM programs [44, 45]. Lewinski et al. found similar barriers among self-management programs for PWE at the program and systems or site levels [46]. A common challenge found among our MEWN program at the systems level was time allotted for the interventions (i.e., scheduling conflicts, understanding of the intervention). Other barriers found in the Lewinski review were not as salient in our self-management programs such as not having written materials for patients since MEWN programs are mostly manualized and provide participants with materials. Hixson et al. similarly found in their review of digital tools for epilepsy management that a primary barrier for clinical staff was lack of payment infrastructure for usage of these programs [47]. This finding from Hixson may partially explain the finding of an implementation barrier in our study related to lack of buy-in among clinical staff and our efforts to build the business case for supporting our programs. These factors are important considerations for the MEWN and other who desire to scale self-management programs in understanding implementation to maintaining programs within the Translational Pipeline model. However, there are future opportunities for research in measuring program fidelity to the intervention guidance among new program adopters in the real-world implementation of these self-management programs beyond research trial settings.

For increasing reach to minority populations with epilepsy in the future, the MEWN programs and future program developers could include these populations in program creation (co-creation) and elicit ways to increase recruitment and should partner with agencies who are gatekeepers to these communities. Our program adaptation efforts to different populations (e.g., Hispanics, youth) also can expand reach to more populations. Related to program maintenance and availability, the principal investigators and project teams implementing MEWN programs have planned for program sustainability in several ways. Many are offering frequent training and technical assistance for interested program implementers. Some have cultivated additional partners for program adoption including affiliates from the Epilepsy Foundation (EF), Epilepsy Alliance and other epilepsy serving community organizations and health systems. These strategies are associated with successful translation of evidence-based programs [48, 49]. In addition, in order to address health inequities, several MEWN programs like UPLIFT have been adapted to AA, as well as Latinos with epilepsy [38]. Adaptation has been seen as a process to sustain evidence-based intervention over time [50].

5 LIMITATIONS

This study has several limitations. First, not all MEWN program teams were included in the study. Only self-management programs that are currently being scaled in this funding cycle were included. Second, respondent bias could have occurred because data were

based on self-reports from the program developers and staff, who may have had limited involvement in research efforts, and may not reflect the views of all MEWN program implementers. Third, other implementation factors (e.g., funding levels) were not assessed with the RE-AIM Framework. Although we used a mixed methods approach for data collection, more intensive interviews with the range of program implementers, including community-based program adopters at the local level could supplement findings by yielding different implementation enabling factors and barriers. Fourth, these efficacy trials of the self-management programs were conducted as part of a funded grant and may not reflect real world context. Future research could involve more data collection with community and clinical organizations delivering these programs for their perspectives. In addition, different programs have different implementation facilitators and challenges in their program lifecycles in terms of effectiveness and other replication trials. We tried to capture these data from the efficacy phase to dissemination efforts to capture those points.

6. FUTURE DIRECTIONS

The MEWN received CDC funding for 2019–2024 to conduct replication studies of the self-management programs described in this study. This study underscores the need for additional implementation research around understanding factors that would lead to optimal reach and participant retention across community-based and clinical settings. We will explore for whom the programs are effective with these replications and adaptations to new PWE populations. Secondly, we are studying how to make the business case for garnering reimbursement for the delivery of our self-management programs. This may lead to more programs undergoing cost analyses to demonstrate potential benefits to payers and justify provider reimbursement. Research from the widely disseminated Chronic Disease Self-Management Program shows the systematic approach undertaken to build evidence of program impact leading to the scalability of that program [51]. Three MEWN programs (UPLIFT, HOBSCOTCH, and PACES) have organizational readiness checklists so that prospective adopters can assess their capacity to deliver the program in areas of staffing, budgets, engagement with audience of interest, referral and recruitment and delivery. These self-assessments may help identify the optimal organizations to adopt the programs before training and implementation occurs. Finally, we are continuing to work with partners to increase the adoption of MEWN programs and exploring best adopters and models of delivery to extend the reach of the programs. As mentioned before, we collaborated with national and regional epilepsy serving organizations and partners through small grants in this effort. In addition, we will continue to disseminate our program findings and information to our program through partners such as the EF and Epilepsy Alliance, through professional networks and conferences (e.g., AES).

7. CONCLUSION

This paper contributes insights into the development of the MEWN self-management programs and their adoption and implementation. The programs have some reach for White and AA PWE, fairly high retention rates and have successful outcomes related to their program aims. We have and continue to plan for sustainability of the programs in terms of training new program implementers, providing ongoing technical assistance, and

making program adaptations, particularly for new populations. This type of implementation research of the program applying the RE-AIM framework contributes to the knowledge base of factors leading to successful program scalability for people with epilepsy and to the scalability of chronic disease self-management programs in general.

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REFERENCES

[1]. Brady TJ, Anderson LA, Kobau R. Chronic disease self-management support: public health perspectives. Frontiers in public health 2015;2: 234. [PubMed: 25964925]

[2]. Helmers SL, Kobau R, Sajatovic M, Jobst BC, Privitera M, Devinsky O, Labiner D, Escoffery C, Begley CE, Shegog R. Self-management in epilepsy: Why and how you should incorporate self-management in your practice. Epilepsy & Behavior 2017;68: 220–224. [PubMed: 28202408]

[3]. Huang X-L, Pan J-H, Chen D, Chen J, Chen F, Hu T-T. Efficacy of lifestyle interventions in patients with type 2 diabetes: a systematic review and meta-analysis. European Journal of Internal Medicine 2016;27: 37–47. [PubMed: 26655787]

[4]. Thorstensson CA, Garellick G, Rystedt H, Dahlberg LE. Better management of patients with osteoarthritis: development and nationwide implementation of an evidence-based supported osteoarthritis self-management programme. Musculoskeletal care 2015;13: 67–75. [PubMed: 25345913]

[5]. Smith ML, Towne SD Jr, Herrera-Venson A, Cameron K, Kulinski KP, Lorig K, Horel SA, Ory MG. Dissemination of chronic disease self-management education (CDSME) programs in the United States: intervention delivery by rurality. International Journal of Environmental Research and Public Health 2017;14: 638. [PubMed: 28613257]

[6]. Tian N, Boring M, Kobau R, Zack MM, Croft JB. Active epilepsy and seizure control in adults—United States, 2013 and 2015. Morbidity and mortality weekly report 2018;67: 437. [PubMed: 29672474]

[7]. England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: Promoting health and understanding.: A summary of the Institute of Medicine report. Epilepsy & Behavior 2012;25: 266–276. [PubMed: 23041175]

[8]. Kobau R, Price PH, Hawkins NA. News from the CDC: translating epilepsy self-management research to practice. Translational behavioral medicine 2012;2: 124–125. [PubMed: 24073104]

[9]. Sajatovic M, Jobst BC, Shegog R, Bamps YA, Begley CE, Fraser RT, Johnson EK, Pandey DK, Quarells RC, Scal P. The managing epilepsy well network:: advancing epilepsy self-management In: Elsevier; 2017. p. S241–S245.

[10]. DiIorio CK, Bamps YA, Edwards AL, Escoffery C, Thompson NJ, Begley CE, Shegog R, Clark NM, Selwa L, Stoll SC. The prevention research centers' managing epilepsy well network. Epilepsy & Behavior 2010;19: 218–224. [PubMed: 20869323]

[11]. Network M. At-a-Glance 2021 In: Well ME, editor.: Centers for Disease Control; 2021.

[12]. Shegog R, Begley C, Chong J, Sepulveda R, Addy R, Martin K, Rosales O, Halavacs N, Labiner D. MINDSET: Clinic-based decision support demonstrates longitudinal efficacy for increased epilepsy self-management adherence among Spanish speaking patients. Epilepsy & Behavior 2020;113: 107552. [PubMed: 33242775]

[13]. Sajatovic M, Tatsuoka C, Welter E, Perzynski AT, Colon-Zimmermann K, Van Doren JR, Bukach A, Lawless ME, Ryan ER, Sturniolo K. Targeted self-management of epilepsy and mental illness for individuals with epilepsy and psychiatric comorbidity. Epilepsy & Behavior 2016;64: 152–159. [PubMed: 27743547]

[14]. Fraser RT, Johnson EK, Lashley S, Barber J, Chaytor N, Miller JW, Ciechanowski P, Temkin N, Caylor L. PACES in epilepsy: results of a self-management randomized controlled trial. Epilepsia 2015;56: 1264–1274. [PubMed: 26122460]

[15]. Sajatovic M, Colon-Zimmermann K, Kahriman M, Fuentes-Casiano E, Liu H, Tatsuoka C, Cassidy KA, Lhatoo S, Einstadter D, Chen P. A 6-month prospective randomized controlled trial of remotely delivered group format epilepsy self-management versus waitlist control for high-risk people with epilepsy. Epilepsia 2018;59: 1684–1695. [PubMed: 30098003]

[16]. Thompson NJ, Walker ER, Obolensky N, Winning A, Barmon C, DiIorio C, Compton MT. Distance delivery of mindfulness-based cognitive therapy for depression: project UPLIFT. Epilepsy & Behavior 2010;19: 247–254. [PubMed: 20851055]

[17]. DiIorio C, Bamps Y, Walker ER, Escoffery C. Results of a research study evaluating WebEase, an online epilepsy self-management program. Epilepsy & Behavior 2011;22: 469–474. [PubMed: 21889413]

[18]. Caller TA, Ferguson RJ, Roth RM, Secore KL, Alexandre FP, Zhao W, Tosteson TD, Henegan PL, Birney K, Jobst BC. A cognitive behavioral intervention (HOBSCOTCH) improves quality of life and attention in epilepsy. Epilepsy & Behavior 2016;57: 111–117. [PubMed: 26943948]

[19]. Wood K, Lawrence M, Jani B, Simpson R, Mercer SW. Mindfulness-based interventions in epilepsy: a systematic review. BMC neurology 2017;17: 1–12. [PubMed: 28056870]

[20]. Michaelis R, Tang V, Wagner JL, Modi AC, LaFrance WC Jr, Goldstein LH, Lundgren T, Reuber M. Cochrane systematic review and meta-analysis of the impact of psychological treatments for people with epilepsy on health-related quality of life. Epilepsia 2018;59: 315–332. [PubMed: 29313968]

[21]. Tabak RG, Khoong EC, Chambers D, Brownson RC. Models in dissemination and implementation research: useful tools in public health services and systems research. Frontiers in Public Health Services and Systems Research 2013;2: 8.

[22]. Brown CH, Curran G, Palinkas LA, Aarons GA, Wells KB, Jones L, Collins LM, Duan N, Mittman BS, Wallace A. An overview of research and evaluation designs for dissemination and implementation. Annual review of public health 2017;38: 1–22.

[23]. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. American journal of public health 1999;89: 1322–1327. [PubMed: 10474547]

[24]. Gaglio B, Shoup JA, Glasgow RE. The RE-AIM framework: a systematic review of use over time. American journal of public health 2013;103: e38–e46.

[25]. Bopp M, Wilcox S, Hooker SP, Butler K, McClorin L, Laken M, Saunders R, Parra-Medina D. Peer reviewed: Using the RE-AIM framework to evaluate a physical activity intervention in churches. Preventing chronic disease 2007;4.

[26]. Brunisholz KD, Kim J, Savitz LA, Hashibe M, Gren LH, Hamilton S, Huynh K, Joy EA. Peer Reviewed: A Formative Evaluation of a Diabetes Prevention Program Using the RE-AIM Framework in a Learning Health Care System, Utah, 2013–2015. Preventing chronic disease 2017;14.

[27]. Glasgow RE, Nelson CC, Strycker LA, King DK. Using RE-AIM metrics to evaluate diabetes self-management support interventions. American journal of preventive medicine 2006;30: 67–73. [PubMed: 16414426]

[28]. Conte KP, Odden MC, Linton NM, Harvey SM. Effectiveness of a scaled-up arthritis self-management program in Oregon: walk with ease. American journal of public health 2016;106: 2227–2230. [PubMed: 27736216]

[29]. Glasgow RE, Harden SM, Gaglio B, Rabin B, Smith ML, Porter GC, Ory MG, Estabrooks PA. RE-AIM planning and evaluation framework: adapting to new science and practice with a 20-year review. Frontiers in public health 2019;7: 64. [PubMed: 30984733]

[30]. Miles MB, Huberman AM, Saldaña J. Qualitative data analysis: A methods sourcebook: Sage publications; 2018.

[31]. Blixen C, Ghearing G, Wade O, Colon-Zimmerman K, Tyrrell M, Sajatovic M. Engaging stakeholders in the refinement of an evidence-based remotely delivered epilepsy self-

management program for rural populations. Epilepsy & Behavior 2021;118: 107942. [PubMed: 33845345]

[32]. Johnson EK, Fraser RT. The Role of Telehealth in the Program for Active Consumer Engagement in Self-management (PACES) in Epilepsy. . In: 123rd Annual Convention of the American Psychological Association Toronto, Ontario; 2015.

[33]. Thompson NJ, McGee RE, Garcia-Williams A, Selwa LM, Stoll SC, Johnson EK, Fraser RT. The impact of a depression self-management intervention on seizure activity. Epilepsy & Behavior 2020;103: 106504. [PubMed: 31648928]

[34]. Johnson EK, Fraser RT, Lashley S, Barber J, Brandling-Bennett EM, Vossler DG, Miller JW, Caylor L, Warheit-Niemi T. Program of Active Consumer Engagement in Self-Management in Epilepsy: replication and extension of a self-management randomized controlled trial. Epilepsia 2020;61: 1129–1141. [PubMed: 32401339]

[35]. Streltzov N, Schimdt S, Zhao W, Roth R, Secore K, Schommer L, Birney K, Jarvis P, Henninger H, Chu F. Improving Quality of Life in Epilepsy: Replication and Generalizability of an Epilepsy Self-Management and Cognitive Training Program (HOBSCOTCH)(S55. 003). In: AAN Enterprises; 2017.

[36]. Schmidt S, Zhao W, Roth R, Schommer L, Yang H, Mazanec M, Chu F, Henninger H, Jobst B. Successful Expansion of Self-Management Practices: A Replication Trial of HOBSCOTCH for Memory Problems in Epilepsy (S3. 001). In: AAN Enterprises; 2019.

[37]. Hunter-Jones J, Nellum A, Olorundare E, McCloud C, Matthew M, McGee R, Davis C, Thompson N, Quarells R. Assessing the cultural appropriateness of UPLIFT for African Americans with epilepsy: a community engaged approach 2016.

[38]. Quarells RC, Spruill TM, Escoffery C, Shallcross A, Montesdeoca J, Diaz L, Payano L, Thompson NJ. Depression self-management in people with epilepsy: Adapting project UPLIFT for underserved populations. Epilepsy & Behavior 2019;99: 106422. [PubMed: 31371202]

[39]. Spruill TM, Friedman D, Diaz L, Butler MJ, Goldfeld KS, O'Kula S, Montesdeoca J, Payano L, Shallcross AJ, Kaur K. Telephone-based depression self-management in Hispanic adults with epilepsy: a pilot randomized controlled trial. Translational Behavioral Medicine 2021.

[40]. Kottapalli I, Needham K, Colón-Zimmermann K, Richter N, Schrag K, Ryan ER, Storer N, Sarna K, Briggs FB, Rentsch J. A community-targeted implementation of self-management for people with epilepsy and a history of negative health events (SMART): A research and community partnership to reduce epilepsy burden. Epilepsy & Behavior 2022;126: 108440. [PubMed: 34920349]

[41]. Luedke MW, Blalock DV, Goldstein KM, Kosinski AS, Sinha SR, Drake C, Lewis JD, Husain AM, Lewinski AA, Shapiro A. Self-management of epilepsy: a systematic review. Annals of internal medicine 2019;171: 117–126. [PubMed: 31261386]

[42]. Shaw EJ, Stokes T, Camosso-Stefinovic J, Baker R, Baker GA, Jacoby A. Self-management education for adults with epilepsy. Cochrane Database of Systematic Reviews 2007.

[43]. Johnson EK, Fraser RT, Miller JW, Temkin N, Barber J, Caylor L, Ciechanowski P, Chaytor N. A comparison of epilepsy self-management needs: provider and patient perspectives. Epilepsy & behavior 2012;25: 150–155. [PubMed: 23032121]

[44]. Perzynski AT, Ramsey RK, Colón-Zimmermann K, Cage J, Welter E, Sajatovic M. Barriers and facilitators to epilepsy self-management for patients with physical and psychological co-morbidity. Chronic illness 2017;13: 188–203. [PubMed: 28783975]

[45]. Ozuna J, Kelly P, Towne A, Hixson J. Self-management in epilepsy care: untapped opportunities. Federal Practitioner 2018;35: S10. [PubMed: 30766395]

[46]. Lewinski AA, Shapiro A, Gierisch JM, Goldstein KM, Blalock DV, Luedke MW, Gordon AM, Bosworth HB, Drake C, Lewis JD. Barriers and facilitators to implementation of epilepsy self-management programs: a systematic review using qualitative evidence synthesis methods. Systematic reviews 2020;9: 1–17. [PubMed: 31907078]

[47]. Hixson JD, Braverman L. Digital tools for epilepsy: opportunities and barriers. Epilepsy Research 2020;162: 106233. [PubMed: 32199221]

[48]. Durlak JA, DuPre EP. Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. American journal of community psychology 2008;41: 327–350. [PubMed: 18322790]

[49]. Sussman S, Valente TW, Rohrbach LA, Skara S, Ann Pentz M. Translation in the health professions: converting science into action. Evaluation & the Health Professions 2006;29: 7–32. [PubMed: 16510878]

[50]. Shelton RC, Chambers DA, Glasgow RE. An extension of RE-AIM to enhance sustainability: addressing dynamic context and promoting health equity over time. Frontiers in Public Health 2020;8: 134. [PubMed: 32478025]

[51]. Lorig KR, Hurwicz M-L, Sobel D, Hobbs M, Ritter PL. A national dissemination of an evidence-based self-management program: a process evaluation study. Patient education and counseling 2005;59: 69–79. [PubMed: 16198220]

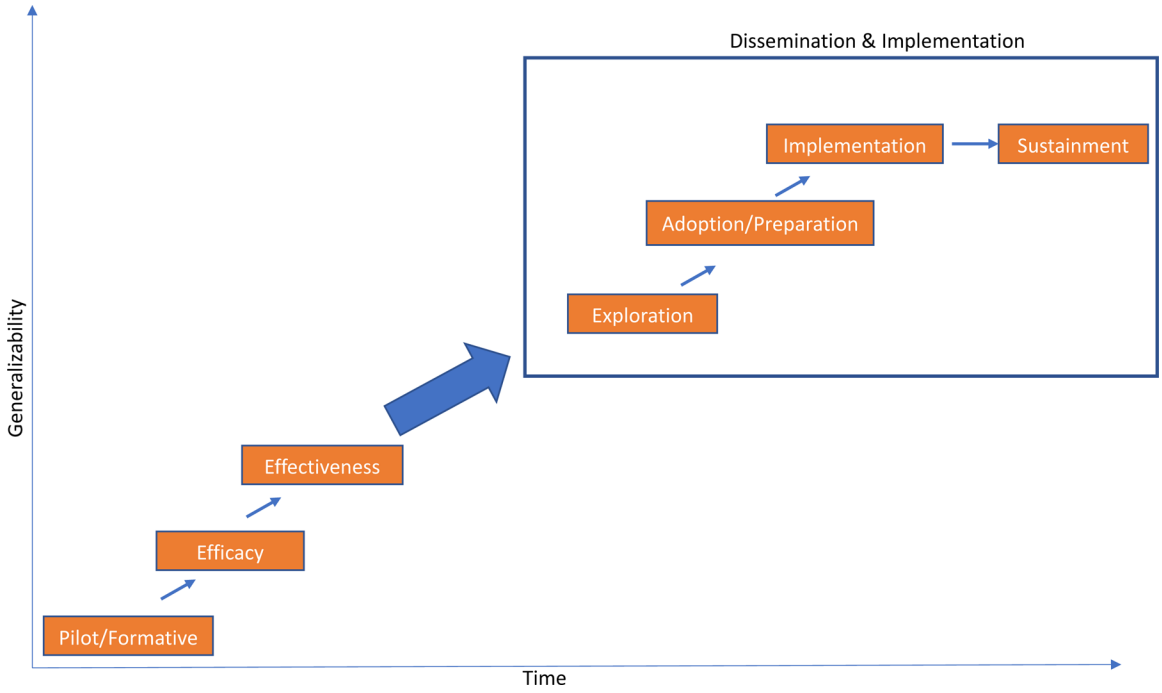

Figure 1:
Translational Pipeline Figure (Adapted from Brown et al. 2017 [22])

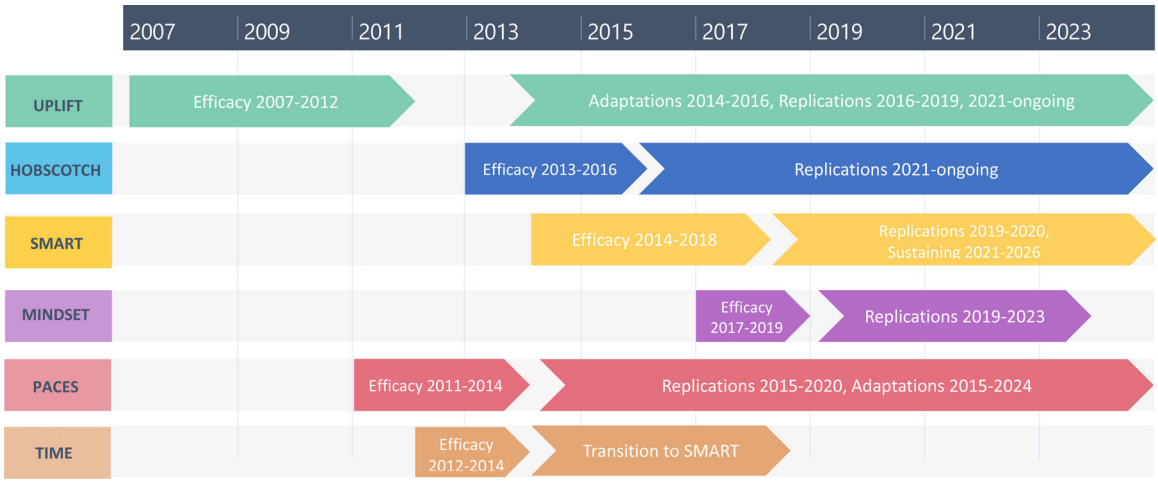

Figure 2:
Timeline of Six MEW Self-management Programs

Table 1.

Key Components of MEW Self-Management Programs

Program	Description	Intervention	Length & # of meetings
UPLIFT	A distance-delivered behavioral program based on mindfulness and cognitive-behavioral therapy distance-designed to address and prevent depression among people with epilepsy	• **Mode**: Group-based (5–7 participants), telephone or web-based • **Components**: Knowledge delivery and skill building in areas including monitoring, challenging, and changing thoughts, attention and mindfulness, coping and relaxing, and preventing relapse • **Delivery**: Trained facilitator and co-facilitator (at least one individual is a person with epilepsy) at each group session	8 weekly telephone sessions, 60 minutes per session
HOBSCOTCH	A behavioral program designed to address memory and attention problems in adults with epilepsy by using Self-Awareness Training, Problem-Solving Therapy and Compensatory Memory Strategies to help adults find ways to manage and cope with memory problems and leader happier, more productive lives	• **Mode:** Initial and final session in-person. Other sessions one-on-one and web/telephone-based • **Components**: Self-Awareness Training, Problem Solving Therapy and Memory and Attention Adaptation Training • **Delivery:** Sessions led by trained memory coach	8 weekly sessions, 45–60 minutes per session
SMART	A behavioral and educational program for adults with sub-optimally controlled epilepsy, especially those who belong to disadvantaged sub-groups (uninsured, veterans)	• **Mode:** Initial session group-based (up to 10 participants) and in-person. Subsequent sessions group-based and virtual, with telephone call-in option. Maintenance sessions via telephone • **Components:** Problem solving, goal setting, nutrition, exercise and social support • **Delivery:** Group sessions delivered by nurse educator and peer educator dyads. Maintenance sessions alternated between nurse educator and peer educator	8 weekly sessions, 60–90 minutes per session, followed by 6 biweekly maintenance phone calls (one-on-one)
MINDSET	A tablet-based decision aid for use in an outpatient healthcare setting to assist both the patients and their health care providers in assessing the patient's epilepsy self-management behaviors relating to seizures, medications, and lifestyle	• **Mode:** Clinic appointment, in-person. Check-up with project staff via telephone • **Components:** Patients complete MINDSET assessment during appointment. Patient and health care providers discuss goals, create strategies, and assess self-efficacy based on non-adherent self-management behaviors identified through MINDSET • **Delivery:** Mindset assessment done with health care provider during visit and check-ins occur with project staff	N/A
PACES	A group-based psychoeducational intervention designed to improve epilepsy and psychosocial self-management	• **Mode:** Group-based (6–8 participatns), in-person • **Components: D**idactic topic-based presentation with discussion and reflection, dedicated time toward individual coping strategies, goal-setting, and progress toward goals. Participants also received weekly mailers related to their specific goals • **Delivery:** Epilepsy rehabilitation psychologist and a peer with epilepsy co-facilitated sessions	8 weekly sessions, 75 minutes per session
TIME	A psychosocial treatment program that blends psychoeducation, problem identification/goal-setting, and behavioral modeling/reinforcement in a group format to improve epilepsy and mental health outcomes among adults with epilepsy and mental illness by increasing care engagement, optimizing use of evidence-based treatment, adopting of health lifestyle to minimize seizure risk and addressing comorbid mental health conditions	• **Mode:** Group-based, in-person • **Components:** Interactive didactic discussion group sessions focusing on self-management topics such as problem solving, goal setting, nutrition, exercise and social support • **Delivery:** Group sessions delivered by nurse educator and peer educator dyads. Maintenance sessions alternated between nurse educator and peer educator	12 weekly sessions, 60–90 minutes per session, followed by 2 maintenance telephone calls (2 weeks apart)

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Table 2.

RE-AIM Dimensions across MEW Self-Management Programs from Efficacy Trials

Program	Reach					Effectiveness		
	Setting(s)	**Socioeconomic Status**	**Personal Characteristics**	**Recruitment Methods**	**No. Recruited & Participants**	**Program Outcomes**	**Major Findings**	**Indicators of success[1]**
UPLIFT	Distance delivery in groups via telephone or web	**Education** Less than College: 60% Completed College: 38% **Income** Not reported	**Gender/Sex** Female: 81% Male: 19% **Race/Ethnicity** Black: 24% White: 74% Other: 2% **Location** Suburban **Represented Intended Population?** No	• Clinic-based • Word of mouth	Recruited: 53 Participants:44 Last follow-up: 31	• Statistically signficant decrease in depressive symptoms in treatment groups vs. treatment as usual (interim assessment). Effect attenuated and non-significant between treatment groups at posttest • Knowledge and skills increased significantly more in intervention vs. treatment as usual from at interim • Satisfcation with life increased in the intervention group • Quality of Life changes were not significantly different between groups • No significant differences in outcomes in telephone delivery vs. web-based delivery	• Depressive symptoms significantly reduced in the treatment group while knowledge and skills increased	• Reduction or prevention of depression • High program satisfaction • Positive engagement/ participation
HOBSCOTCH	Mix of clinic, in-person delivery and web-based or telephone delivery, all sessions in groups	**Education** Less than College: 41% Completed College: 59% **Income** Not reported	**Gender/Sex** Female: 66% Male: 34% **Race/Ethnicity** Not reported **Location** Rural/suburban **Represented Intended Population?** Yes	• Word of mouth • Organizational website • Organizational listerv • Recruitment through partner organizations (Managing Epilepsy Well network, American Epilepsy Society)	Participants: 66 Last follow-up: 49	• Significant improvements in quality of life in treatment groups vs. control • Significant reduction in cognitive dysfunction in treatment groups vs. control • Non-significant reduction in depression symptoms in treatment groups vs. control	Both intervention arms show significant improvemet in quality of life and reduction in cognitive dysfuntion compared to control	• Steady growth of program awareness & delivery • Professional group interest • Positive participant & memory coach feedback
SMART	Distance delivery via telephone or	**Education** Less than high school: 16%	**Gender/Sex** Female: 68.1% Male 31.9%	• Electronic medical records search of two	Participants: 120	• Significant reduction in total negative health events at 6 months vs. waitlist	Intervention group demonstrated significant	• Steady growth of program

Program	Reach			Recruitment Methods	No. Recruited & Participants	Effectiveness		
	Setting(s)	Socioeconomic Status	Personal Characteristics			Program Outcomes	Major Findings	Indicators of success[1]
	web, group-based	High school: 27.7% More than high school: 56.3% **Income** <$25k: 87.4% ≥$25k: 12.6%	**Race/ethnicity** Black: 69.9% White: 30.1% Hispanic: 7.6% **Location** Urban **Represented Intended Population?** Yes	urban medical health systems Outreach by regional epilepsy-focused social services agency • Clinical referrals • Print and electronic advertising	Last follow-up: 103	• Signficant reduction in depression symptions at 6 months vs. waitlist • Significant improvement in quality of life at 6 months in treatment vs. waitlist • Significant improvements in epilepsy self efficacy and self-management at 6 months in treatment vs. waitlist • No difference in seizure severity at 6 months between treatment group vs. waitlist	improvements in several domains including reduced depression, improved quality of life, and improved behavioral outcomes related to self-management	awareness & delivery • Current adoption byepilepsy-focused social services agencies in urban and rural communities in Ohio, Pennsylvania, West Virginia, and Kentucky
MINDSET	Tablet based delivery during clinical appointments, individual patients	**Education** Less than College: 59.6% Completed College: 40.4% **Income** < $25k: 58% $25-$50k: 18% ≥$50k: 29%	**Gender/Sex** Female 53.2% Male 46.81% **Race/Ethnicity** Hispanic: 100% **Location** Urban/suburban **Represented Intended Population?** Yes	• Health care provider reviewed patient records for study eligibility and recruited at clinic appointments	Participants: 94 Last follow-up: 91	• Self-management adherence improved by third visit in treatment group vs. treatment as usual for 5 self-management behaviors in domains of seizure management, lifestyle management, and information management. • Frequency of adherence behaviors improved to a greater degree in the treatment group vs. treatment as usual • Among those in the treatment group, greater adherence associated with particpants who set adherence goals	Implementation of MINDSET within regular neurology visits may assist Hispanic adults with epilepsy to increase their adherence to epilepsy self-mangement behaviors and maintain this adherence longitudinally Adherence to self-management behaviors was more likely if patients selected goals to increase those behaviors than if they did not select goals	• Increased adherence to self-management behaviors
PACES	Clinic-based in-person delivery, group	**Education** Less than College: 40% Completed College: 48% Completed more than college: 11% **Income** < $25k: 22%	**Gender/Sex** Female: 62% Male: 38% **Race/Ethnicity** Black: 6% White: 89% Asian: 4% Hispanic: 6% Other 2%	• Word of mouth • Clinic-based • Print and mail advertisement	Participants: 106 Last follow-up: 82	• At 8 weeks, there were significant reductions in depression symptoms and improvements in epilepsy self management, epilepsy self-efficacy and quality of life in treatment vs. control group	Promising improvements in most of the outcomes analyzed including depression, self-management and self-efficacy immediately following	• Retention rate • Positive outcomes • Participant satisfaction

Program	Reach					Effectiveness		
	Setting(s)	Socioeconomic Status	Personal Characteristics	Recruitment Methods	No. Recruited & Participants	Program Outcomes	Major Findings	Indicators of success[1]
		$25-$50k: 32% ≥$50k: 46%	**Location** Urban **Represented Intended Population?** No			• At 6 months, epilepsy self-management and some domains of quality of life remained significantly improved (emotional well-being, medication effects) • At 8 weeks, participants improved significantly on epilepsy self efficacy and overall psychosocial distress • At six months, epilepsy self-management and self-efficacy remained improved as well as psychosocial distress. • At 12 months, epilepsy self-management and psychsocial distress lowered	intervention in the treatment group. Epilepsy self-management and overall lowered psychosocial distress were more robust to improvements at one year	
TIME	In-person, group based	**Education** Less than college: 25% **Income** < $25k: 96%	**Gender/Sex** Female 59% Male 41% **Race/Ethnicity** Black: 57% White: 36% Hispanic: 7% **Location** Urban **Represented Intended Population?** Yes	• Electronic health records earch • Word of mouth • Organization website • Recruitment from other partners • In-person health fair • Clinic referrals	Participants: 44 Analyzed: 35	• Significant reduction in depression symptions in treatment vs. treatment as usual group. • High acceptability of program reported by participants	• Positive impact of program on depression symptoms	Improvement in participants depression severity

[1] Indicators of success refer to respondents perception of program growth after initial efficacy study

Table 3.

RE-AIM Dimensions across MEW Self-Management Programs

Program	Adoption		Implementation			Maintenance	
	Single-site or multi-site program	Program deliverer	Retention Rate (% Completed)	Recruitment Feasibility	Program delivery barriers	Plan to continue program	Steps taken to continue program
UPLIFT	**Single-Site:** • Emory University	• Person with Epilepsy • Graduate Research Assistant • Licensed clinical psychologist	73%	Time and scheduling conflicts were recruitment barriers	• Institutionalization • Infrastructure needed to deliver program • Need enough appropriate staffing/ people to deliver program • Aligning schedules of participants for group sessions • Access to licensed mental health professionals	No. Conducted an additional trial at Morehouse School of Medicine but currently do not have funding for additional delivery	• Training & technical assistance • Explore differential facilitators/barriers to implementation
HOBSCOTCH	**Multi-Site:** • Dartmouth Hitchock Medical Center • Maine Medical Center • University of Massachusetts Medical Center • University of Vermont Epilepsy Center	• Researcher • Licensed clinician • Trained healthcare staff • Trained Memory Coach	74.24%	No barriers reported	• Community partner funding • Financial sustainability • Protected staff time to deliver program • High turnover of trained personnel at community sites	Yes	• Dissemination training • Additional staff hiring • Revising training and support • New CDC grant funding
SMART	**Multi-Site (all in Ohio):** • Academic setting • Safety net hospital system • Veteran Affairs	• Trained person with epilepsy (peer educator) • Nurse	86%	No barriers reported	• Internet access was a barrier for some (although phone participation could/was used by individuals with limited web access s	Yes	• Adoption byAepilepsy-focused social services agencies in Ohio, Pennsylania, West Vergina, and Kentucky with CDC funding • Broader-based training curriculum or nurses and peer educators
MINDSET	**Multi-Site** • 3 clinics with Epilepsy Foundation Central South Texas • 2 clinics in Banner Health (Arizona)	• Trained healthcare staff • Research assistant	96.8%	Potentially missd eligible patients during recruitment due to insufficient staffing/resources on clinic days	• Adaptation • Personnel and staffing issues • Outdated software/ architecture / software updates	No	• Sustained in epilepsy foundation Central South Texas through CDC grant funding

Program	Adoption		Implementation			Maintenance	
	Single-site or multi-site program	**Program deliverer**	**Retention Rate (% Completed)**	**Recruitment Feasibility**	**Program delivery barriers**	**Plan to continue program**	**Steps taken to continue program**
				with many eligible patients	• Initially unclear if it would be well received in the clinic or be perceived as beneficial by patients and providers • Getting program up and running		
PACES	**Single** • University of Washington	• Researchers (licensed psychologists) • Trained peer with Epilepsy	92%	No barriers reported	• Seen as research program rather than something that could be adopted clinically • Transportation to medical center • Administrative buy in • Staff time • Financial sustainability • clinical program/service line	Yes Subsequent trials expanded reach to community hospitals/non-academic epilepsy centers. Also, Hispanic and Teen trials done in Texas and California	• Training & technical assistance
TIME	**Single** • Cleveland, OH metropolitan area	• Trained healthcare staff • Person with Epilepsy	Arm 1 86% Arm 2 73%	Delays in recruitment and in-person format were recruitment barriers	• Time for project coordinator • In person delivery burdensome for some • Difficulty in getting providers (nurses, peer educators) compensated for their time and effort • support staff	No. TIME transition to SMART stutdy	• Plans to develop a virtually-delivered version of the

Table 4.

Dissemination Efforts of MEW Self-Management Programs and Lessons Learned

Program	Adaptations/Replications	Dissemination	Lessons Learned
UPLIFT	• African American • Spanish-Speaking	• Training for additional UPLIFT facilitators • Monthly training and technical assistance for those trained • Foundationimplementation	• Funding for program has helped engage new facilitators • Training and technical assistance calls reveal challenges with recruitment and scheduling • Telehealth format of UPLIFT generated increased uptake during COVID-19
HOBSCOTCH	N/A	• Epilepsy Foundation Affiliates • Epilepsy Centers	• Funding for implementation sites • Marketing and promotion of programs in multiple sectors • Ongoing funding for training and implementation support
SMART	The team is currently seeking support to adapt SMART for adolescents and young adults (AYA) with epilepsyepilepsy	• Partnership with 3 epilepsy social services agencies to deliver SMART program to existing and new clients • Case Western Reserve University training nurse educators and peer educators to deliver SMART outside of research setting	• Online format of SMART generalized well to COVID-19 • As more people with epilepsy become comfortable with telehealth, they seemed amenable to participating in the remotely delivered SMART program • Barriers related to scaling-up SMART: problems with digital access, logistic barriers embedded in the coordination of group-format on-line sessions and limited opportunities for healthcare providers to be compensated for training and program delivery
MINDSET	Spanish-speaking	• Sustained in Epilepsy Foundation Central South Texas through grant funding • Implemented with University of Arizona at Banner Health clinics due to funding and pre-existing collaboration	• A digital behavioral change intervention appears feasible for use in epilepsy clinic settings. • Use of a goal-based action plan to assist decision making can facilitate improved self-management behaviors and patient-provider communication. • Patient literacy needs to be considered to mitigate challenges of comprehension, reading, and writing.
PACES	Rural-dwelling adults Telehealth-based Veterans Spanish-Speaking Adolescents (age 14–17)	• EpilepsyTraining for PACES facilitator dyads • Monthly training and technical assistance for those trained • Targeted partners include epilepsy-focused non-profits (e.g., service-based community organizations) and Epilepsy clinics in medical centers	• Funding PACES dissemination ongoing challenge at all sites and needs to be sustained • Use epilepsy foundation grants, mental health codes, and current procedural terminology codes • Training and technical assistance and resources needed for site launch and sustainment efforts • Need MEW to collaborate on marketing self-management programs • Evidence base for telehealth options attractive to program adopters during COVID-19 • No “one size fits all” commercialization model.
TIME	Relevant elements of TIME (coping with stigma, managing stress and mood, managing interpersonal	N/A	• Programs need to be relatively brief and able to be virtually delivered

Program			
	Adaptations/Replications	**Dissemination**	**Lessons Learned**
	conflicts) were incorporated into the SMART interventionintervention		