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BRIEF REPORTS

Better Together: Evolution of Patient Stakeholder Engagement in Healthy Lifestyle Research After Acquired Brain Injury

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Engaging stakeholders in the conduction of research is increasingly recognized as beneficial and necessary in order to gain valuable insights. The following narrative describes the process of engaging and partnering with patient stakeholders in a six-year systematic line of research to modify an evidence-based healthy lifestyle program called the Diabetes Prevention Program Group Lifestyle Balance (DPP-GLB) for individuals with acquired brain injury (ABI), including traumatic brain injury (TBI) and cerebrovascular accident/stroke (CVA). We will describe how patient stakeholders were regularly engaged and encouraged to offer feedback to support study activities, including curriculum modification, research design, knowledge translation, and future research opportunities, to create a meaningful and patient-centered program for people with ABI. Commentary from two patient stakeholders who have been part of the modification, implementation, and dissemination of both programs is also included. Additionally, the importance of including patient stakeholders in all stages of research and future directions of the modified programs are discussed from the perspective of our research team.

Introduction

Engaging stakeholders in the conduction of research is increasingly recognized as a beneficial and necessary element of academic research (Frank et al., 2015; Warren et al., 2018). Patient, community (e.g., family, caregivers, community members), and other (e.g., clinicians, researchers, and policy makers) stakeholders offer unique, diverse, and real-world perspectives of current health issues to create more meaningful and applicable research questions (Harrison et al., 2019). The benefits of engaging stakeholders in the research process may include improving the study design and associated outcomes, ensuring cultural appropriateness of materials, increasing recruitment and retention of research subjects, empowering patient stakeholders to share their voice, and injecting democracy, transparency, and accountability into the research process (Harrison et al., 2019).

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In 2015, our research team engaged stakeholders from one local stroke support group and one local traumatic brain injury model system (TBIMS) advisory board to identify unmet community needs for people with acquired brain injury (ABI). These groups included patients, caregivers, community members, and clinicians. Stakeholders' primary recommendation was the provision of opportunities to improve health, with a specific need to support a healthy lifestyle. Stakeholders noted specific barriers and needs, including the need to support weight loss due to mobility issues, a lack of appropriate community-based programs, and lack of a knowledgeable resource to meet their physical activity and nutrition goals. As one stakeholder indicated:

> ...lifestyle changes have had a profound positive impact on me. One of the first changes was with my diet. I was also able to obtain a NuStep early on that I have ridden regularly, starting when I was right-sided hemiplegic, unable to do much of anything. These are not things that every survivor would be able to duplicate. Programs to promote a healthy lifestyle for survivors in the community do not exist, but being knowledgeable about exercise and diet has been so important for me to stay healthy, and improve everything about my life. — *Male, 33 years old*

Another stakeholder shared that:

> I always enjoyed working out, dancing, hiking, etc. before my injury. However, it has taken a deeper meaning now. It's my way of surviving and coping. — *Female, 56 years old*

Based on this feedback, the need for an evidence-based healthy lifestyle program tailored for people post-ABI became clear. Stakeholders also emphasized that they would prefer a group-based program to facilitate social connections with other people who had experienced ABI.

After reviewing existing evidence-based programs, our research team identified the Diabetes Prevention Program Group Lifestyle Balance program (DPP-GLB) (Kramer et al., 2011) as a possible solution, specifically because it is group-based and had been previously modified for people with disability, although not for people with TBI or stroke (Betts & Froehlich-Grobe, 2017). The DPP-GLB is a 12-month, 22-session healthy lifestyle program that has been used extensively with the general population. As researchers, we subsequently engaged stakeholders, including individuals from this original stroke support group and TBIMS advisory board, through a community-based participatory research approach (Drum et al., 2009; White et al., 2001) to support the modification, implementation, and dissemination of the DPP-GLB to meet the unique needs of individuals with ABI (Driver et al., 2017, 2020). Community-based participatory research empowers stakeholders to work collaboratively and is recognized as crucial for research involving people with disabilities (Drum et al., 2009; White et al., 2001). Stakeholder engagement in the DPP-GLB modification and implementation process started with a one-day advisory board meeting and was sustained through continued meetings, directed queries, and expanded roles and partnerships. The purpose of this paper is to describe the process we followed to formally engage patient, community, and other stakeholders in our subsequent research efforts. Though our overall engagement process included a variety of stakeholders (e.g., patient, community, and other), the following discussion focuses primarily on the evolution of our patient stakeholder engagement. This is because the roles and scope of their involvement changed significantly over the six year partnership with our research team.

Methods

Stakeholder Engagement to Support Program Modification

The DPP-GLB adaptation process involved three phases: 1) engaging stakeholders to identify appropriate adaptations to the DPP-GLB; 2) making the relevant modifications to create the GLB-CVA and GLB-TBI; and 3) obtaining approval from the stakeholders to ensure that the modifications accurately reflected their recommendations. To achieve this, we convened two separate stakeholder groups, one for TBI and one for CVA (N=39 total stakeholders, including former patients, caregivers, physiatrists, researchers, rehabilitation therapists, neuropsychologists, exercise specialists, dietitians, community partners, and DPP-GLB lifestyle coaches) for a one-day advisory board meeting to discuss necessary program modifications (Driver et al., 2017, 2020). Stakeholders were identified and chosen based on need and expertise (e.g., clinical, lived, scientific, community-based) and previous partnerships with the research and clinical team (e.g., original stroke support group and TBIMS advisory board). Two weeks before attending the meeting, all stakeholders were sent the original DPP-GLB materials and a series of open-ended, plain-language questions to review in advance. These initial questions and subsequent topics of discussion covered during the in-person meeting were derived from evidence-based approaches to modifying healthy lifestyle programs (CDC, 2010; Rimmer et al., 2014) and included: 1) introduction to the DPP-GLB program and purpose of the meeting; 2) modifications and supports for physical activity (45-minute discussion during meeting); 3) dietary restrictions, cooking adaptations, and considerations for healthy eating in the ABI population (45 minutes); 4) unique barriers and behaviors to consider when modifying the program (1 hour); and 5) logistics and program delivery (45 minutes). Each topic was introduced by a member of the research team, stakeholders were able to ask clarifying questions, and were then divided into smaller groups of 3–5 individuals to discuss in more detail for 20–25 minutes. Small groups consisted of a representative from each stakeholder category (patient, community, and other (clinical, policy makers)) to allow for diverse feedback and discussion. The large group then reconvened, and a member of the research team facilitated feedback from each group, which was then recorded into a spreadsheet. Examples of recommendations from stakeholders included: 1) incorporating subject matter experts (i.e., ABI physical therapists, ABI dietitians) into classes to address participant questions; 2) emphasizing heart health and risk for recurrent stroke; 3) modifying recommended daily sodium content for people with stroke; 4) involving caregivers in classes to provide support (e.g., emotional, informational, transportation, meal preparation); 5) including videos and resources for safe exercise options beyond walking (e.g., chair exercises, adapted yoga); 6) using wrist-based step trackers versus the GLB-recommended waist-worn pedometer to capture movement for people with lower-limb mobility impairment; 7) updating the language throughout to reflect "movements" instead of "steps"; and 8) creating a local community resource list (e.g., local workout facilities that specialize in adapted movement, local farm stands, local support groups for people with ABI) (Driver et al., 2017, 2020). Stakeholders were reimbursed $100 for their time and participation in this one-day meeting.

After collating recommendations, the research team adapted the program materials to develop the GLB-CVA and GLB-TBI. Any conflicting recommendations were reviewed with a smaller group of stakeholders and resolutions were determined based on feasibility and applicability. These materials were then shared with faculty at the University of Pittsburgh Diabetes and Prevention Support Center to ensure the modifications maintained the integrity of the DPP-GLB while meeting the unique needs of people post-CVA and TBI. After receiving approval, the GLB-CVA and GLB-TBI were shared with stakeholders to confirm that the modifications appropriately reflected their original feedback. This initial engagement process with our stakeholders was the start of a fruitful and reciprocally beneficial relationship that has grown over the last six years.

Patient Stakeholder Engagement During the Research Process

Notably, as the research evolved, so did the role of our patient stakeholders. Many of these changes were not by design, but directed by the constant engagement, investment, and continued dialogue between our patient stakeholders and research team. It is important to note that not all patient stakeholders involved in the initial one-day meeting (n=6) sustained their involvement in the same way over time, most due to time constraints. All six individuals were involved in updates and feedback requests; however, new patient stakeholders were also recruited from community partnerships and previous research projects (n=37). Engagement of patient stakeholders occurred in several ways and activities were optional for stakeholders based on time availability and interest. Examples of engagement opportunities included: 1) piloting our research surveys and providing feedback; 2) providing guidance on eligibility criteria and outcome assessments; 3) testing mobile applications to support participant engagement; 4) reviewing factsheets for usability; 5) attending quarterly meetings; and 6) informing future grant applications. Feedback resulted in many changes, including: 1) reduced length of surveys administered to study participants; 2) expanded eligibility criteria to include people over the age of 65 in our GLB-CVA study; 3) modification of a mobile application to include more positive affirmations; 4) health-literate factsheets on barriers to weight loss for people with ABI; and 5) the incorporation of patient stakeholders as members of the study team on future grant applications.

Critically, several (n=25) of our patient stakeholders' roles evolved and they became peer mentors and active components of the intervention. The decision to include peer mentors in classes was based on feedback from former participants and stakeholders (Douglas et al., 2019) and the success (e.g., feasibility, greater participant satisfaction, greater participant weight loss) of other peer-supported and peer-led healthy lifestyle and self-management programs (Aschbrenner et al., 2015; Cabassa et al., 2015). As peer mentors, patient stakeholders shared their lived experience by joining classes (both in-person and virtual), providing support (emotional and informational), sharing their lived experience with participants as well as their knowledge about exercise and healthy eating as someone with an ABI, and teaching perseverance in overcoming barriers to healthy lifestyles. Peer mentors also met with a healthy lifestyle coach before each session to discuss their role, feedback they wanted to provide, and address any questions they had. Peer mentors were paid $100 per session and attended a maximum of six sessions each year.

Feedback from our research participants has been overwhelmingly positive. Results of an electronic exit survey administered at the completion of the program indicated participants: 1) felt connected to the peer mentors; 2) attributed much of their success in the program to the peer mentors; and 3) thought the peer mentors provided inspiration, positivity, and proof that success in the program is possible. As a result, our research team has worked to expand both programs from local delivery to national audiences. The perspectives of our patient stakeholders who became peer mentors significantly shaped this future direction. The following discussion includes commentary from two patient stakeholders—who later became peer mentors—who have been part of the modification, implementation, and dissemination of both modified DPP-GLB programs.

Patient Stakeholder Stories & Perspectives

Audrey's Story

I experienced a severe TBI in 2013 when I had a motor vehicle collision on my way to classes at a local college. I spent 39 days hospitalized in acute care, four months in in-patient rehabilitation, and many months and years of outpatient therapy learning to eat, walk, talk, and live independently again. My mother and I participated in many research studies as participants during and after my hospital stay. The research team approached me in 2015 to be part of our first advisory board to help modify the DPP-GLB program for individuals with TBI. Since 2015, my mother and I have continued to participate as stakeholders and peer mentors in the GLB-TBI program and have also expanded our engagement in research to become stakeholders on projects supported by the Patient-Centered Outcomes Research Institute (PCORI).

Audrey's Perspective

The GLB-TBI program is crucial for individuals who are recovering from a TBI. Knowing that you are not alone in this life after gaining a disability truly is encouraging and helps one move forward in the process of recovery. I believe that the importance of the program applies to *anyone*—no matter what "category" they fall under. We all need to be aware of our diet, physical activity, emotional well-being, and community engagement behaviors. We all need to be recognized. We all need to know that we matter and that we make a difference with our contributions in this life we lead. It is crucial to acknowledge that every individual is different in the recovery process and that everyone has a unique way of dealing with the cards they have been dealt in this life.

As a patient stakeholder I have gained a broader perspective on the recovery process and life in general. I am very thankful to have begun this journey as a patient stakeholder because it has offered me a broader perspective on health, the world, and the medical community. This was very important to the role that I have held–TBI peer mentor–and I have found that has helped me in my recovery process along with the fact that it has helped others along their own recovery process. It is so important to have perspectives of patients that are recovering and have gone through injury. As researchers, we can learn so much from individuals with this life experience.

I am very excited that this research is moving forward, and that the information gained is being applied. As a recovering TBI patient and peer mentor, I am encouraged by the progress that is being made, what has been discovered and recognized, and that the focus seems to be that everyone has value and worth—that we *can* and *will* move forward along our journey in life no matter what has been thrown our way. I am very thankful and glad to be a part of this study. I feel that I am a valuable member of the research team, and it has opened my mind and eyes to the benefit of research and ability for us to help others.

Emily's Story

I suffered a stroke in 2014 while I was seven months pregnant with my daughter. I was healthy, had no underlying conditions, and no explanation for my stroke. I spent months in inpatient rehabilitation learning to regain the use of the right side of my body and live independently again. I safely delivered my daughter two months later and was able to take her home where I continued my outpatient rehabilitation journey. I am a theatre teacher and remained connected to the rehabilitation program staff after my injury. I was approached by the research team in 2017 to serve on an advisory board to create the GLB-CVA and I have been a peer mentor for the past two years.

Emily's Perspective

After my stroke, I had to discover how to live a "new normal" and continue thriving and improving post-stroke. It is all about how you react and how you recover. I never believed it when they told me that I would never regain all that

I lost. My world was rocked when I had my stroke in 2014 and I believe that it is important for survivors to take control of their story because it never truly ends. Six years post-stroke I still believe I am improving daily.

Professionally, I am a teacher. At home, I am a mom. Acting as a peer mentor in the GLB-CVA program, however, is a different type of "teacher." I believe this role allowed me to teach stroke survivors how to continue to grow and thrive even during difficult times. I believe that the voice of peer mentors is vital. As survivors, we must be the voice for those who will go through what we did. Personally, too, it has allowed me to give back to the institution that helped me get my life back.

Watching this program evolve over the last few years has truly been inspiring. It started as a conversation and has become something so much bigger. I believe the program really benefits all involved, whether you are a doctor, therapist, coach, mentor, caregiver, or survivor. It provides survivors with tools that they need to take back their life and allows them to celebrate milestones and victories with other group members. The GLB-CVA program has allowed me to gain a different perspective on the stroke recovery process. Though I lived it, seeing others with similar experiences has been eye-opening—it is true that no two strokes are the same. Though everyone's journey is different, it is important not to do it alone.

Conclusion

Stakeholder perspectives throughout our research process have been critically important to ensuring study goals and project activities are meaningful and patient-centered. The engagement of our patient stakeholders has also grown our research team's understanding of the scope, value, and importance of partnering with patients in research. Though our research team has decades of experience working with people with ABI, no team members have lived experience. Our patient stakeholders have helped create a more health-literate (e.g., factsheets, modified curriculum), patient-centered (e.g., including peer mentors and caregivers), and meaningful program for people with TBI and stroke, which would not have been possible with our research team alone.

We have also learned of the benefit to patient stakeholders when you truly partner with them throughout the research process, as described through Audrey and Emily's perspectives. It is important to also highlight the involvement of patient stakeholders throughout the entire research process. As the research process continued, patient stakeholders' perceptions and knowledge changed, which led to their roles and scope of engagement evolving over time. What started as a one-day stakeholder meeting quickly grew to continued and involved engagement as well as two-way dialogue between the patient stakeholders and research team, much of which was driven by our patient stakeholders themselves. Based on the efforts of our patient stakeholders, our work with the DPP-GLB program has been significantly shaped and these relationships have given our research team a deeper understanding of the importance of engagement for individuals after ABI.

Further, data from the GLB-TBI and GLB-CVA studies support the efficacy of the modified curricula as participants (n=140) lost weight (5–8%), attended classes (>85% attendance), and improved their health outcomes (e.g., blood pressure, diabetes risk, hypertension, triglycerides, and self-efficacy). Additionally, as an important step in making the program widely available to people with a brain injury living in the community, our team submitted and received approval for the GLB-TBI and GLB-CVA curricula and leaders guides by the Centers for Disease Control and Prevention Diabetes Prevention Recognition Program (CDC-DPRP). This is the first step to qualifying for Centers for Medicare and Medicaid Services (CMS) reimbursement and would not have been possible without the support and input of our stakeholders.

In the future, our patient stakeholders and researchers have identified knowledge translation (i.e., creating training modules for trained GLB coaches to deliver the modified program to people with TBI and stroke) and effectiveness/scale-up studies (e.g., virtual delivery, app-supported) so the program can be delivered broadly and in real-world settings. Additionally, we identified a need for incorporating people with lived ABI experience as trained GLB coaches to deliver the program, a method that has been proven feasible in other DPP-GLB programs but has not been adapted for individuals with disability (Kulik et al., 2015; Mizushima et al., 2021; Young et al., 2017). As noted, our initial process evolved significantly over time and made for a more meaningful experience for both our researchers and patient stakeholders, which is reflected in our sustained patient stakeholder involvement, partnership, and research study success and evolution.

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