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A Conceptual Model to Promote the Retention of Women With Physical Disabilities in Research

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Abstract

Inadequate participant recruitment and retention practices can affect sample representativeness and thus the generalizability of research findings. Retention of research participants has been examined within the literature to some extent; however, there is no consensus on best practice in achieving acceptable results. Furthermore, there is a gap in understanding how to engage and retain women with physical disabilities (WPDs) in research. To address these oversights, we review (1) the significance of retention as a methodologic concern, (2) factors that influence the involvement and retention of participants in research, including individual, population, and health-illness considerations, and (3) particular circumstances impacting the inclusion and retention of WPDs in research. Based on a review of the literature and our experience with the Healing Pathways randomized-controlled trial (RCT), we present a conceptual model to guide culturally-sensitive health research implementation with WPDs, and promote the engagement and retention of this group in RCTs and other forms of interventional health research.

Keywords

disability; prospective studies; partnerships; program planning

Introduction

Women with physical disabilities (WPDs) experience a plethora of social, economic, educational, and health inequities, and there is limited evidence-based research applicable and translatable to improving their experience (Pyatak, Blanche, Garber, Diaz, Blanchard,

Florindez, & Clark, 2013). As such, there is an urgent and critical need to conduct research with this group to promote their health and overall quality of life (Pyatak et al., 2013). However, given the complexity of WPDs day-to-day life experience, engaging in research, particularly protocols that are time-intensive, is not necessarily a priority for this group. This is problematic, because to generalize health-related research findings the National Institutes of Health recommends that study samples represent the target population as closely as possible (National Institutes of Health [NIH], 2001).

It is unrealistic to expect perfect retention in research. For randomized-controlled trials (RCTs), twenty to 30% attrition is considered tolerable; More than this may reflect serious flaws (or bias) in the study and affect validity (Amico, 2009). Attrition bias occurs when participants who complete all follow-up measurements differ significantly from those lost to attrition, particularly when their differentiating characteristics correlate with study variables of interest (Gluud, 2006). Researchers can minimize bias through appropriate research design and effective recruitment and retention measures (Robinson, Dennison, Wayman, Pronovost & Needham, 2007). The purpose of this article is to offer a conceptual model for consideration in implementing research intended to impact WPDs. Our model includes four key principles reflective of the approach we used with this group to promote their recruitment, attendance, and participation in an ongoing community-based participatory research study. We based our model on an examination of the relevant literature and reflections on our experiences implementing the Healing Pathways trial.

Literature Review

We performed a search of electronic databases including PubMed, Medline, PsychINFO, CINAHL, SCOPUS, and Google Scholar using the key words “recruitment,” “retention,” “attrition,” and “dropout.” We paired and/or strung these keywords in various arrangements with secondary terms including “human subjects,” “research participants,” “women,” “clinical trial,” “research design,” “prospective research,” “best-practice,” “strategies,” “disability,” and “community-based research.” Search limits were used where possible to specify journal articles, systematic reviews, meta-analyses, and evaluation studies published from 2007–2014. No matter the search terms or strings used, returned citations were generally disparate in their content and relevance to the retention of women with physical disabilities in research. Thus, it was necessary to conduct a hand-search of each returned citation to identify and select articles most relevant to the topic for deeper examination of this gap.

In general, findings of our review revealed that retention of research participants has been studied in specific populations, in many cases related to certain health-illness conditions (Robinson et al., 2007). Methods employed to promote the retention of research participants are diverse and highly specific to individual studies. Although retention strategies have been explored systematically in some cases (Booker, Harding, & Benzeval, 2011; Brueton, Tierney, Stenning, Meredith, Harding, Nazareth, Rait, & 2014; Robinson et al., 2007), these reviews and/or analyses indicated that retention efforts and outcomes are generally poorly reported, and the diversity of the strategies used by researchers makes it difficult to assess or quantify the impact of any one strategy or a set of strategies on retention outcomes.

Furthermore, sparse information exists on maximizing the retention of participants in studies requiring in-person follow-up (Robinson et al., 2007). To date no reviews or single studies for that matter, have examined efforts to retain WPDs in time-intensive RCTs or other forms of prospective interventional health research.

Factors influencing the involvement and retention of people in research

Within the literature, it is clear that recruitment strategies and retention outcomes are intertwined. It is also well documented that retention issues are highly nuanced and most often vary by participant, population, and problem under investigation. General participant characteristics affecting both recruitment and retention have been thoroughly identified. These include age; gender; ethnicity; marital status; illness severity; functional status; comorbidities; education or literacy level; financial, social, and logistical supports; perceived study benefits; altruism; and likelihood of therapeutic results. Personal health beliefs and perceptions regarding control; risk; privacy; financial status and well-being; and logistical coordination and support for participation have also been noted to impact individual engagement and retention in research (Bell, Hammond, Hart, Bickett, Temkin, & Dikmen, 2008; Lengacher, Gonzalez, Giuliano, Bennett, Cox, & Reintgen, 2001; Kneipp, Lutz, & Means, 2009).

Ethnicity, culture, and perceived or actual social standing are other influential factors impacting an individual's willingness to engage or stay in a research study. Persons from ethnic minorities or other underrepresented groups (e.g., persons of lower socioeconomic status or with various types of disabilities) may exclude themselves from health research because of distrust of the research process, inaccessible information, competing personal demands, uncertainty of the intervention and/or its effectiveness, fear of discrimination, differential treatment, or breach of confidentiality, and immigrant status (George, Duran, & Norris, 2014). Conversely, sociocultural beliefs about illness and health-seeking behaviors, altruistic desires, perceived study benefits, and accessibility of culturally-sensitive study interventions appeal to the willingness of individuals from minority groups to participate in research (George et al., 2014).

Population-based factors also contribute to difficulties with recruitment and retention. For example, people experiencing trauma, functional impairment, or homelessness are more likely to have lower socioeconomic status, move often, and have substance abuse or psychiatric problems that interfere with follow-up (Pyatak et al., 2013). Age, cognitive and functional status, higher incidence of chronic illness, lessened capacity to understand verbal and written information, as well as transportation issues can affect the recruitment and retention of older adults in research (Bonk, 2010).

Specific health-illness designations can create other confounding factors impacting recruitment and retention of study participants. For example, illness severity and trajectory may inhibit the enrollment, adherence, and retention of participants with certain cancer diagnoses (Boonzaier, Pollard, Ftanou, Couper, Schofield, Mileshekin, & Henderson, 2010). Attempts to recruit participants with psychiatric diagnoses may illuminate care issues that inhibit recruitment or retention as well. For example, qualified individuals currently receiving mental health treatment might be reluctant to give up existing services or begin a

new pharmacologic protocol required for research participation (Macias, Gold, Hargreaves, Aronson, Bickman, Barreira, et al., 2009). In un-blinded studies, preference or dislike of group assignment and treatment can affect participants' willingness to continue (Macias, et al., 2009).

Factors influencing the involvement and retention of WPDs in research

The National Institutes of Health Revitalization Act of 1993 and its 2000 amendment mandated the inclusion of women and minorities in funded clinical and biomedical studies (NIH, 2001). This mandate facilitated the inclusion of underrepresented populations, but members of these groups continue to face barriers to research participation (Barnett, Aguilar, Brittner, & Bonuck, 2012). For women of minority status, these hurdles may include language barriers, financial issues, homelessness, limited social support, lack of transportation, and cultural differences (Barnett et al., 2012). Factors that may additionally impact the involvement and retention of WPDs in research include the physical environment and accessibility, and health, economic, social, and educational disparities (Drum et al., 2009). Compared to women without disabilities, WPDs are significantly more likely to be single, unemployed, have less than a high school education, have inadequate access to health care, and live below the federal poverty line (United States Census Bureau, 2012). Health disparities affecting this group include access to care, preventative health services, and health information, and higher rates of illness (World Health Organization [WHO], 2013).

For WPDs, barriers to research participation may be compounded by stigma, experiences of discrimination, and secondary conditions (Drum, Peterson, Culley, Krahn, Heller, Kimpton, et al., 2009). Importantly, WPDs are disadvantaged more by disability and complications of primary disabling conditions than by race or ethnicity (WHO, 2013). Primary disabling conditions are generally medical, physical, cognitive, emotional, or psychiatric and are considered to interfere with daily activities, functional level, and quality of life (Drum et al., 2009). In addition, WPDs on average experience no fewer than 16 intermittent or chronic secondary conditions, all of which may worsen with age (Kinne, Patrick, & Doyle, 2004). These include, but are not limited to, fatigue, injury, depression, obesity, pain, and pressure ulcers. Such preventable conditions create barriers to health resources and research opportunities for WPDs, owing in part to architectural, equipment, policy, and attitudinal barriers, not to mention health care provider knowledge gaps related to disability (Drum et al., 2009). Given these serious inequities, it can be difficult to recruit, engage, and retain WPDs in research, especially if the contextual aspects of their experience are not adequately addressed, underscoring the importance of using culturally-sensitive approaches with members of this population (Drum et al., 2009; Pyatak, et al., 2013).

The Healing Pathways Trial

We conducted a randomized controlled trial called Healing Pathways (HP) using a community-based participatory research (CBPR) approach. Using a CBPR approach means that members of our participating communities were full partners in the selection of the research design and implementation of the study. In our case, the partnership determined the RCT as the method of choice for the HP study. The research sample included WPDs with significant depression who required some form of accommodation. Participants were

retained for 14 weeks to test the efficacy (or therapeutic benefit) of the HP program. In brief, HP is a cognitive-behavioral, strengths-based, peer-facilitated, group-therapy program for WPDs with depression (Hassouneh, Nguyen, Chen, & McNeff, 2013). The goal of the program is to reduce depression symptoms by focusing on self-empowerment (Hassouneh et al., 2013). For the trial, we expected participants to attend a weekly 2.5-hour group therapy sessions for 14 weeks in addition to participating in data collection activities. Their participation involved pre-reading, homework, and sharing experiences during sessions. See Hassouneh et al. (2013) for results of the HP clinical trial. The trial has concluded; however, the partnership continues, with HP extending to several additional communities.

Principles and Strategies to Promote the Retention of WPDs

Our HP trial had an overall retention rate of 81 percent (Hassouneh et al., 2013). Specifically, we retained 95 percent of participants in the experimental group and 67 percent in the control/wait-list group (Hassouneh et al., 2013). Control group participation exceeded one year and wait time to enroll in the wait-listed intervention was 6.5 months. Participants who were enrolled in the study earlier in the recruitment period waited even longer. Dropout from the control group was primarily attributed to the extended wait time to treatment. Notwithstanding, we believe our attention to four key principles in study design and implementation was a critical factor in achieving our retention results. Thus, we recommend researchers implementing prospective clinical trials, or other methods of interventional health research requiring a significant time commitment of WPDs, consider the following culturally-sensitive principles in implementation of the research project:

1. A community-based participatory approach is most effective in identifying the health-related needs and risks relevant to WPDs.
2. Research teams that are fluid and dynamic in their membership and consistently promote the full inclusion of persons with disabilities are best situated to develop, implement, and evaluate programs impacting the health of WPDs.
3. Consumer-driven interventions promote independence of WPDs as participants in research.
4. Person-centered research implementation supports the engagement of WPDs in study-related activities and thus their retention in research.

We will briefly explain these guiding principles in the context of the recruitment and retention literature and our experience with the HP program. We will then provide details specific to principle #4, elaborating specifically on the person-centered strategies we used for retaining WPDs in the HP trial.

Principle 1: A community-based participatory approach is most effective in identifying the health-related needs and risks relevant to WPDs

Research design and methodologic choices can influence the engagement of women and minorities in health-related studies, as well as their adherence to elements of the research project. The literature recommends that investigators working with these groups involve individuals from the target population in research efforts to ensure full understanding of the

needs of the community as well as alignment of investigator-community interests, motivations, and goals (Drum et al., 2009; Robinson et al., 2007). CBPR is typically used to address health disparities and promote health in underserved populations (Israel, Eng, Schulz, Parker, & Satcher, 2005). Program development via CBPR is cyclical and iterative (Israel et al., 2005) and is best suited for minimizing the burden of research for participants (Robinson et al., 2007). CBPR allows flexibility in study design decisions and promotes investigator actions that are open and responsive to ethnocultural nuances of the population (Israel et al., 2005).

An essential component of CBPR is informing and educating the target community regarding the process and rationale for its use. In the HP trial, we partnered with WPDs in the target community to align academic and community health goals and develop trust. This partnership was critical, as many individuals with physical disabilities distrust researchers and feel alienated by the health care system (Oliver & Barnes, 2012). Often, disability research does not reflect the lives of individuals with disabilities, and they regard the results as irrelevant (Oliver & Barnes, 2012). We knew that making assumptions about health-related needs of WPDs without their feedback and opinion at project outset would inhibit potential positive outcomes.

As the partnership developed, we discovered issues requiring attention to promote full inclusion of WPDs in the research, specifically human resource, training, accommodation, funding, and productivity-related challenges (Hassouneh, Alcala-Moss, & McNeff, 2011). Such issues can affect investigators' ability to adhere to the study protocol and timeline. Overcoming barriers to the full inclusion of WPDs in research may be costly, but proactive planning can surmount this. Hassouneh and colleagues (2011) offer practical strategies for mitigating these potential barriers. Despite the complexity it adds to the research process, we assert that the CBPR approach is itself a retention strategy, with great potential to minimize attrition of WPDs in clinical trials and other forms of prospective interventional health research. See Hassouneh, et al. (2011) for details on the HP partnership and research methodology.

Principle 2: Research teams that are fluid and dynamic in their membership and consistently promote the full inclusion of persons with disabilities are best situated to develop, implement, and evaluate programs impacting the health of WPDs

Researcher characteristics can play a major role in retention. Initial interactions between team members and potential participants may affect individuals' decisions to enroll (Kneipp et al., 2009; Monson, Parlour, Simcock, Fallowfield, & Jenkins, 2012). Alignment (or misalignment) of research team members' race, gender, appearance, or manner with the target population may also affect recruitment and retention (George et al., 2014). Team members' interpersonal skills facilitate or hinder retention efforts as well. Research team behaviors that reflect caring, nonjudgment, and support of participants influence perceived trust and rapport, and in turn participants' willingness to adhere to required protocols (Kneipp et al., 2009; Penckofer, Byrn, Mumby, & Ferrans, 2011). The research team's relationship with the referral base (e.g., individual providers, clinical staff, community organizations) may also influence participant engagement. Related factors include team

members' or referrers' motivations and commitments to the research; perceptions regarding roles; time constraints; competing priorities; communication; decision-making practices; and research-related literacy specific to the project (Carr, Davis, Spencer, Smart, Hudson, Freeman, et al., 2010; Hassouneh et al., 2011).

In the HP trial, we included as many team members from the target population (WPDs) in the development and implementation of the study as were available and willing to participate within the study timeframe (Hassouneh et al., 2011). We recruited team members to ensure investigator-community alignment on the health issue of concern and population health values and goals. Team membership included investigators; directors and staff of disability resource agencies; individuals with physical disabilities active within the disability community; and students. WPDs from the target population served as peers, key research team informants, and gatekeepers of study implementation procedures. It should be noted, however, that although each person with a disability on the team was considered a peer of WPDs, not all were perceived as members of the disability culture or community. Like other cultures, disability includes social structures and nuances not necessarily apparent to those outside the community. Disability culture incorporates hierarchies related to the extent of functional impairment as well as the type of equipment used to facilitate function. Our efforts in assembling the team were consistent with recommendations from the literature to align study team characteristics with those of the target population in all phases of the research process. WPDs from the target population did, however, comprise the majority of the research team throughout the duration of the project.

We provided extensive, accessible training for those assuming critical roles to ensure competence of team members regarding interpersonal skills, research literacy, and program evaluation. As mentioned, we discovered logistical tensions in our efforts to promote full inclusion of all team members in varied aspects of the trial. Strategies to proactively address barriers stemming from constraints and rigidity of experimental design and funding streams are presented elsewhere (see Hassouneh et al., 2011). Although the trial concluded, we are continuing to implement the HP program in other locales. As a result, our team membership has grown substantially to incorporate additional community stakeholders. The fluid and dynamic membership of our research team, comprising a majority of persons with physical disabilities and/or persons active within our target population, was key to the development, implementation, and ongoing evaluation of the HP program. The team itself and most importantly the peer model we employed were critical for promoting the retention of participants in the HP trial.

Principle 3: Consumer-driven interventions promote independence of WPDs as participants in research

Findings from interventional health research specific to persons with disabilities have implications for health policy and program funding decisions, and involving persons with physical disabilities in the development of a health-related intervention is likely to ensure its feasibility and relevance for the target population (Kewman, 2001). Incorporating the views of prospective consumers, specifically with respect to feasibility, ensures greater independence and participation of members of the target population (Pyatak, et al., 2013).

Independent living is an essential value in disability culture (National Council on Independent Living [NCIL], 2014). A consumer-driven independent living model applied in health research promotes this value by addressing environmental and attitudinal barriers that might disempower or inhibit the independence of persons with disabilities from participating in interventions or research programs intended to promote their health.

Consumers with physical disabilities as members of our research team were key to identifying feasibility-related issues and proactively implementing solutions that facilitated independence and self-determination of WPDs participating in the program. Including consumers with physical disabilities in our research planning and implementation processes promoted engagement and independence of prospective participants, as well as their retention.

Principle 4: Person-centered research strategies support the engagement of WPDs in study-related activities [including recruitment, attendance, and participation] and thus their retention in research

Methods of recruitment, enrollment, and screening and the contexts in which these occur influence study enrollment and retention (Bell et al., 2008; Robinson et al., 2007). The timing of these processes, extent and readability of study materials, and availability of assistive technology and diverse forms of media, as well as physical accessibility and recruitment support, may influence participants' intent to enroll in a research study (Drum et al., 2009). In general, recruitment strategies fall into two categories – active and passive (Cooley, Sarna, Brown, Williams, Chernecky, Padilla, et al., 2003). Active strategies require the investigator to contact potential participants directly via personal letters, phone calls, or presentations at community events or social groups. Passive strategies require participants to contact the investigator after receipt of study information (e.g., via newspaper ads, radio announcements, posters, and pamphlets). Regardless of method, the literature indicates that screening of potential participants for study readiness, motivation, and ability to engage in the required protocol may be most influential in terms of retention results (Lengacher et al., 2001). Informing potential participants of the burden of the study during screening and informed consent procedures may enhance confidence in enrollment, reduce the possibility of attrition, and increase overall retention rates (Lengacher et al., 2001; Robinson et al., 2007).

Other strategies reported to promote participant adherence and retention include maintaining contact with participants between scheduled appointments (Robinson et al., 2007); regularly updating participant contact information (Pyatak et al., 2013); sending birthday, holiday, or thank you cards (Lengacher et al., 2001); arranging transportation for research-related appointments (Bell et al., 2008); providing incentives for participation and/or compensation for travel (Robinson et al., 2007; Brueton et al., 2014); establishing a one-to-one relationship between each participant and a single research team member (Lengacher et al., 2001); and using creative strategies (e.g., voter registration registries, vital statistics registries, local newspaper obituaries) to find participants lost to follow-up (Bell et al., 2008; Pyatak, 2014). There is sparse evidence that any specific set of strategies maximizes retention (Robinson et al., 2007). As such, it is recommended that investigators use a diverse collection of

strategies and minimize participant burden by making necessary protocol modifications (Robinson et al., 2007).

We used a variety of strategies aligned with our guiding principles that were effective in promoting retention. We concentrated our efforts in three primary areas: recruitment, attendance, and participation (see Figure I). Although these aspects of study implementation are interrelated, we will attempt to differentiate our work in each area for clarity, translatability, and usefulness.

Recruitment—In terms of recruitment, we centered our approach on creating a barrier-free environment. We partnered with several durable medical equipment (DME) companies to get information about the HP study directly to potential participants. We identified geographic areas closest to the intervention site and then worked with DME companies to target informational mailings to potential participants (see Krahn, McCarthy, Westwood, & Powers, 2008 for more information on this type of university-private partnership recruitment method). The mailings were prepared to promote ease of physical accessibility; specific glue and paper clips were selected to ensure that women with upper-extremity physical or sensory impairments could open the mailing and sort through the included materials on their own. Because of assumed educational disparities within our potential recruitment pool, we formatted and presented informational materials in a manner accessible to those with potentially low literacy levels. We used Flesch-Kincaid readability tests to improve our materials, presenting them at a fifth-grade reading level.

We recruited WPDs directly in their communities. We considered population-based economic forces affecting WPDs, as well as community agencies and resources used by this group, assuming economic ebb and flow, as well as specific consumer patterns. We set up recruitment efforts at various consumer locations, such as grocery stores and laundromats on the first of each month, and then searched newspaper and grocery store advertisements in the middle of the month to find sales of potential interest to WPDs. We identified additional store locations and set up booths to promote the program with study fliers. Recruiters assisted interested WPDs on the spot with completion of the screening and enrollment paperwork. At the end of the month, recruiters connected with WPDs at local food banks, including study fliers in outgoing food sacks. We notified WPDs about the study both passively (via posters/fliers) and actively at locations such as bus stops, laundromats, utility payment sites, hospitals, postal offices, physical therapy clinics, and centers for independent living, as well as community events. We also used certain provider lists and marijuana registries to reach potential participants. It took several months to recruit the targeted number of WPDs ($N = 80$); however, establishing partnerships with local disability service agencies and getting to know the demographic characteristics of our potential participant pool, as well as economic and consumer-oriented behavior patterns, contributed to the engagement of WPDs in the trial.

Women were excluded from the trial if they self-identified as having a cognitive disability and/or were suicidal. Screening involved the completion of several assessment tools including the Center for Epidemiologic Studies Depression Scale, Suicide Behaviors Questionnaire, Danger Assessment, and questions to rule out cognitive disability and active

psychosis. We also assessed potential participants for group readiness. Recruiters sought WPDs who demonstrated motivation or eagerness to participate and a clear understanding of the intent of the program and time commitment required.

Attendance—We defined attendance as showing up for HP group sessions. We sought to create a welcoming, comfortable, barrier-free environment. This required assessment of our spaces/facilities, as well as community services, including transportation and other accommodation resources. For WPDs, transportation and parking can be monumental hurdles that deter attendance. We ensured that participants had transportation to and from group sessions each week and also provided stipends to supplement transit costs, which we offered in addition to monetary incentives for ongoing participation. We also provided refreshments at each session. We considered facilities that would easily accommodate all participants, with space for maneuverability and storage of assistive devices. The team provided individualized accommodations based on participant requests to ensure their attendance and comfort. Examples included provision of personal assistance during group sessions, money for childcare to support attendance, and ergonomic chairs. Showing up to group sessions facilitated peer-to-peer relationships and promoted attendance. Though not encountered in the HP trial, it should be noted that group membership standing is a factor that might deter attendance for some (Brown, Long, Gould, Weitz, & Milliken, 2000).

To further encourage attendance, team members, including the project coordinator, facilitators, and personal assistants, made weekly phone calls to all participants to check in on those who might benefit from extra support and encouragement and to remind participants about the next group session. Reminder calls were made the day before group sessions and included time for relationship building. The calls lasted approximately two to 45 minutes. Team members started conversations with, “How are you doing?” They listened to responses and at times refocused the participant on something positive. Team members tracked small, yet significant, pieces of personal information, so they could then refer to them later. Often, participants simply wanted to be listened to; many were lonely or isolated. Having the opportunity to share their feelings about what was happening in their daily lives by phone and between sessions cultivated rapport and trust between participants and HP team members. The team affirmed that this relationship-building activity was the key success factor that minimized issues related to attendance. No obligatory attendance standard was prescribed; however, most participants chose to attend consistently. There were instances of health issues, illness, and hospitalization; however, those affected continued to look forward to their weekly phone calls and therefore were able to continue to participate in one form or another. In these situations, peer group members provided support and encouragement to those unable to attend. In some instances, hospitalized participants were visited by a HP team member/peer and were assisted in the completion of homework.

Participation—Participation meant active engagement with HP study materials and regular contribution to group sessions. It was essential that the materials were accessible across disability experience. The HP Women’s Workbook was provided to all participants free of charge in either/both written and electronic formats. We created all text with literacy in mind and accommodated individuals with a fifth grade or higher reading level. Some

participants required the hard copy of the workbook to be in larger print, and others needed the background paper to be yellow versus white for reading comfort. These accommodations and others were made as needs arose.

HP peer facilitators trained in the materials and formal group process assessed participants' contribution to group sessions. Facilitators assessed learning styles with Kolb's Learning Styles Inventory (Kolb, 1976), which helped them recognize variances in group dynamics and attend to the individual learning needs of each participant. The designation of a trained primary peer facilitator and co-facilitator was a key success factor in the area of participation, promoting the psychological safety of all participants. The facilitators led discussions on specific, sometimes sensitive, topics and ensured adequate coverage of all of the HP material. Facilitators prepped themselves on the materials before each session, kept the group on time, and minimized or addressed any uncivil situations that arose. In addition, they debriefed together after each session to consider what went well and opportunities for improvement. Implementation of group guidelines at initial group formation, and review of these guidelines at the start of each session, was one strategy that minimized group disruption and maximized participants' focus on the HP materials.

Peer facilitators found group size to be a factor in some participants' ability/willingness to participate during sessions. Some participants were more quiet and reserved than others or just not used to sharing in a group format. Facilitator skill in this context cannot be overemphasized. Our facilitators were trained to ensure equal opportunity for all to participate. The HP program offers a facilitator manual as one component of training. The manual includes tips for facilitators that promote the inclusive engagement of all participants and offers information on common group process pitfalls and strategies for minimizing group challenges while maximizing experience.

Facilitators encountered a few hurdles in running the HP groups. Some women did not want to participate owing to health issues, sensitivity regarding certain topics, fear or personal motivation factors. Facilitators kept in more frequent contact with these women, worked with them one-on-one at times, and/or spent time breaking down the HP content to more manageable segments. They also aimed to determine the root cause of participation issues; once core needs were addressed, participation issues were resolved or minimized.

Conclusion

Based on the literature, we illuminated several factors that affect the recruitment and retention of participants in research. These can be categorized as general and contextual, personal and population-based, and variable based upon specific health-illness designation under study. For WPDs, additional complexities and inequities relevant to their experience complicate recruitment and retention of this group in research. However, potential factors contributing to sampling bias in studies involving WPDs can be minimized via culturally sensitive research implementation, including the use of multiple person-centered strategies geared toward promoting the retention of a representative sample. Upon reflection from the HP trial, we presented a conceptual model offering four guiding principles for study implementation that promote the retention of WPDs in research. We further specified

person-centered strategies that we used aligned with our guiding principles and relevant to the recruitment, attendance, and participation of this group. For the HP trial, attention to the research approach; team composition; intervention relevance and feasibility; and the implementation of person-centered strategies were critical success factors that helped us engage and retain participants.

Most research relevant to participant retention is heterogeneous in nature and thus difficult to quantify. Thus, it may be fruitless to compare the effectiveness of highly nuanced strategies across studies. Though it is worthwhile to conduct research comparing the costs and benefits of various retention strategies within a particular study, results of such inquiry require cautious implementation in studies involving other persons or groups with specific health-illness designations. In studies involving WPDs, it may be beneficial to examine researchers' adherence to the four principles we outlined herein and subsequent impact of adherence on retention outcomes. Moreover, we recommend testing of the four principles we highlighted in this article for translatability and usefulness in similar forms of research with WPDs. We believe that these recommendations will be useful and relevant to researchers implementing alternate methods of interventional health research with WPDs in the future as well.

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*** Guiding Principles that promote the retention of WPDs in research:**

1. Implement a community-based participatory approach in study design.
2. Promote the full inclusion of WPDs on the research team.
3. Ensure the study intervention is consumer-driven.
4. **Use person-centered strategies to promote the recruitment, attendance, and participation of WPDs in research.**

Attendance Strategies

- Assess space & facilities for accessibility and comfort
- Proactively address access issues
- Ensure accessible transport to/from study site
- Offer alternative locations for intervention implementation on a case-by-case basis
- Provide weekly check-in & reminder phone calls
- Implement incentives or accommodations that alleviate the burden of attendance

Recruitment Strategies

- Identify and eliminate potential barriers to recruitment opportunities
- Ensure ease of physical accessibility to study materials
- Verify materials are at appropriate literacy levels
- Use information on population-based consumer patterns to facilitate recruitment directly within the community
- Use a variety of active and passive strategies to meet diverse needs
- Partner with local agencies offering consumer services to WPDs

Participation Strategies

- Make materials economically-friendly and accessible across disability experience
- Implement individualized accommodations
- Use trained peer facilitators who promote consistent & inclusive group processes
- Ensure optimal group size and function for the comfort of all individuals

Figure I.

Culturally-sensitive study design: Promoting the retention of women with physical disabilities in research