

A five state dissemination of a community-based disability prevention program for older adults

Elizabeth A Phelan¹
Barbara Williams²
Susan J Snyder³
Sally Sizer Fitts¹
James P LoGerfo⁴

¹Department of Medicine, Division of Gerontology and Geriatric Medicine, University of Washington, Seattle, WA, USA; ²Department of Health Services, School of Public Health and Community Medicine, University of Washington, Seattle, WA, USA; ³Senior Services of Seattle/King County, Seattle, WA, USA; ⁴Department of Medicine, Division of General Medicine, University of Washington, Seattle, WA, USA

Objective: To describe challenges in disseminating the Health Enhancement Program (HEP), a community-based disability prevention program for community dwelling elders, and to examine program effectiveness in geographically dispersed sites.

Methods: Within-group, pre-test–post-test comparisons of disability risk factors, health and functional status, and hospitalizations for 115 participants completing one year in HEP, and primary care provider awareness and perceptions of the program.

Results: Most (77%) participants were women, with an average age of 73 years and an average of 3.5 chronic conditions. At one-year follow-up, compared with enrollment, fewer participants were depressed (8.8% vs 15.9%), physically inactive (15.8% vs 38.6%), at high nutritional risk (24.3% vs 44.1%), or experiencing restricted activity days (35% vs 48%). Severity scores on most measures also improved significantly. The proportion hospitalized was unchanged from the year prior to HEP, although risk factors predicted an increase in hospitalizations as for the control group in the randomized trial.

Conclusions: HEP reduced participants' disability risk factors. Sites varied on numbers enrolled and time to implement the program, likely due to differing referral bases, degree of physician awareness of HEP, and site readiness. However, the benefits of HEP participation were comparable with those reported previously.

Keywords: aged, risk factors, outcome and process assessment (healthcare), chronic disease self-management, diffusion of innovation, program evaluation

Introduction

The Health Enhancement Program (HEP) is a community-based wellness intervention designed to preserve the health and functioning of older adults who reside in the community and have a high risk of functional decline due to chronic health problems (Leveille et al 1998). In a departure from traditional interventions, which emphasize disease-specific knowledge, specialty expertise, and technical skills (Bodenheimer et al 2002; Grumbach and Bodenheimer 2002), and which have had mixed results in changing health behaviors and outcomes (Norris et al 2001), HEP emphasizes collaborative, patient-centered, disease self-management. Recent studies among individuals with various chronic diseases suggest that teaching patients disease-related self-management skills and increasing their self-efficacy, or confidence in their ability to manage their chronic disease, may be a beneficial way to improve health outcomes (Rimal 2000; Bodenheimer et al 2002; Bandura 2004). As part of the HEP intervention, trained staff (nurses and social workers) identify potentially modifiable risk factors for disability (eg, depression, poor nutrition, sedentary lifestyle) for each participant and employ motivational strategies to promote behavior change to reduce those risk factors in order to prevent subsequent functional decline. HEP staff deliver the program in community settings and maintain ongoing communication with each participant's primary care physician (PCP). A randomized trial conducted at one

Correspondence: Elizabeth A Phelan
Division of Gerontology and Geriatric Medicine, University of Washington, 325
9th Avenue, Box 359755, Seattle, WA
98104-2499, USA
Tel +1 206 744 9112
Fax +1 206 744 9976
Email phelane@u.washington.edu.

senior center in western Washington state in the mid-1990s demonstrated the efficacy of this intervention: HEP participants had less functional decline and fewer hospitalizations than those in the control group (Leveille et al 1998). Local dissemination of HEP demonstrated its effectiveness at various other sites in western Washington with a larger number of staff. Older adults enrolled for one year reduced their risk of disability, improved their health status, had less functional decline, and avoided the increase in hospitalization predicted by baseline risk factors (Phelan, Williams, Leveille, et al 2002).

Based on local success, the Robert Wood Johnson Foundation (RWJF) began funding a national dissemination of HEP in 2001. The primary goal of the national dissemination was to determine how well HEP could be implemented in settings that serve minority, low-income, and rural populations and to measure its impact in those settings (Glasgow et al 2003). With this goal, HEP sites were established in five other states using the same dissemination model that had been successful within Washington state. The overall enrollment target at the outset of the funding period was 700 participants. We also note an independent implementation of a very similar program, called Health Matters, that enrolled a lower-risk population at one site in California (Holland et al 2003; Leveille et al 2004; Tidwell et al 2004). Both the importance and the inherent difficulty of such translational research are increasingly recognized, as highly effective programs have faced substantial challenges and barriers to large-scale dissemination (Olds 2002; Gross et al 2004). We planned the present evaluation to determine whether the impact of one year of HEP participation at new, widely dispersed sites was comparable with benefits observed in the efficacy trial and effectiveness study of HEP. If the benefits in geographically widespread and newly developed venues were similar to those observed in previous trials, then policy discussions focused on making the program widely available might be warranted.

Methods

Setting

The intervention was conducted at thirteen senior centers in western Washington that had been involved with the local dissemination of HEP (Phelan, Williams, Leveille, et al 2002) as well as twelve community or senior centers in five other states where HEP was newly established with the support of RWJF funding: Portland, Maine; Albany, New

York; Portage, Vicksburg, Comstock, and Kalamazoo, Michigan; Chicago, Illinois, and Sacramento and Carmichael, California. All but one of these settings had expressed interest in implementing the program prior to the RWJF funding being secured by Senior Services of Seattle/King County (SSSKC); the funding made it possible for these sites to actually mount the program. Community settings were desired because they can offer, and encourage participants to become involved with, core elements of the intervention: chronic disease self-management (CDSM classes) (Lorig et al 1999), regular exercise (Lifetime Fitness Program [LFP] or other group program) (Wallace et al 1998), and social connections (eg, HEP health mentor, volunteer work, group meals and trips) (Davis et al 1998).

Participants

HEP targets ambulatory, community-dwelling adults with at least one chronic illness who therefore are at risk for functional decline. In keeping with the targeting criteria used in the efficacy trial (Leveille et al 1998), the five-state dissemination excluded participants with dementia or terminal disease. From 1 July 2002 through 31 December 2002, 224 adults enrolled in HEP. The present analyses include all participants due for one-year follow-up on or before 31 December 2003. Local staff recruited participants via letters, signed by and mailed from their primary care provider's (PCP's) office, recommending HEP and giving the name and phone number of the nearest HEP nurse. The letter encouraged potential enrollees to call the HEP nurse. If a call was not received, the nurse called the potential enrollee, explained the program, and invited him/her to come to the site. PCP practices were affiliated with healthcare systems that contributed financially to HEP, usually in the form of salary support for the HEP nurse. Patients whom PCPs indicated were inappropriate for the program (non-ambulatory, having dementia, or other terminal illness) did not receive a letter. Community case managers, social workers, or individuals in similar positions also referred potential participants whom they recognized as being at risk for functional decline and likely to benefit from the HEP program. Other participants self-referred in response to newspaper articles, flyers, advertisements in the senior center newsletter, and presentations to groups at the site and to health and social service providers.

Intervention

The HEP intervention is based on the conceptual model of disability formulated by Buchner and Wagner (1992). This model suggests that predictors of (ie, risk factors for) disability such as poor chronic disease control, physical inactivity, and social isolation can be modified in order to reduce susceptibility to functional decline. The HEP nurse conducts an initial assessment of each participant's health and functional status and risk factors for disability and works with the participant to develop a "health action plan". This personalized plan, tailored to each participant's individual goals and preferences, addresses one or more disability risk factors identified by the nurse's assessment. All participants are encouraged but not required to enroll in three core components of the intervention described previously (CDSM, LFP, HEP health mentor) (Davis et al 1998; Wallace et al 1998; Lorig et al 1999). Participants with psychosocial issues such as depression are encouraged to meet with the HEP social worker.

Data collection

Data collection focused on health and functional outcomes, adherence to the program (specifically, frequency of participation in core components of HEP), and hospitalization. Participants reported this information on written questionnaires at enrollment and again at 6 and 12 months after enrollment. The HEP nurse mailed the questionnaire to the participant in advance of the initial and follow-up assessments to allow the participant to complete it as his or her own pace. The participant then brought the questionnaire in for the assessment visit with the nurse. If the questionnaire was incomplete at the time of the visit, the nurse assisted the participant in completing it. The nurse next reviewed the participant's responses for completeness and accuracy and then, with the participant present, transferred the questionnaire information into WellWare[®], a secure, data-entry software program that has been internet-accessible since 1 January 2003. Sociodemographic information was also collected and entered at the initial visit. Once entered, data were stored in a database at SSSKC. Staff of SSSKC removed all personal identifiers and then transmitted these data to researchers at the University of Washington for analysis. The University of Washington's institutional review board approved the data collection procedures.

Risk factors

We used well established scales to measure three modifiable risk factors for disability: (1) 15-item Geriatric Depression Scale (GDS) (Sheikh and Yesavage 1986), on which a score greater than five is suggestive of depression; (2) Physician-based Assessment and Counseling for Exercise (PACE) scale (Long et al 1996), on which a score of four or less (exercising only infrequently) corresponds to being physically inactive; and (3) Nutrition Screening Initiative (NSI) DETERMINE (Disease, Eating poorly, Tooth loss or mouth pain, Economic hardship, Reduced social contact, Multiple medications, Involuntary weight loss or gain, Need for assistance in self-care, Elderly) instrument (Posner et al 1993), on which a score of 4 or more indicates nutritional risk and a greater likelihood of poor health at baseline and functional disability a year later.

Functional status and mobility

We assessed functional status using the National Health Interview Survey (NHIS) bed disability days questions: "In the past 12 months, did you stay in bed because of illness or injury? If yes, how many days did you stay in bed?" Previous analyses have shown that this measure is able to detect (ie, it is responsive to) important changes in functional status in relatively healthy elderly populations over time (Wagner et al 1993). We also assessed functional status with two NHIS restricted-activity day questions analogous to the bed disability days questions (Scholes et al 1991). We assessed mobility with four yes/no questions: "Because of your health, do you have any difficulty climbing one flight of stairs? Several flights?" and "Because of your health, do you have any difficulty walking one block? Several blocks?" Functional assessment also included difficulty with basic activities of daily living (ADL) function, ie, bathing, dressing, toileting, transferring in and out of bed, and feeding (Katz et al 1963).

Health status and hospitalization

We used the Medical Outcomes Study (MOS) question on self-rated health as a measure of health status (Ware and Sherbourne 1992; McHorney et al 1993, 1994). The following questions provided information on hospitalization in the 12 months before and after enrollment by self-report: "In the past 12 months, were you ever in the hospital overnight for physical health problems? If yes, how many days were you in the hospital overnight?" Participants completed a checklist to indicate which of seven chronic medical conditions (heart problems, diabetes, hypertension,

arthritis, emphysema, nervous or emotional problems, cataract) had been diagnosed by a physician.

We assessed PCP awareness of their patients' participation in HEP and their own impressions of the benefits of HEP via a brief questionnaire mailed to PCPs by the HEP nurse in June 2003. There were 210 PCPs who were mailed a questionnaire.

Sample size

With 224 participants, we had greater than 90% power to detect a change of one point or more on the PACE instrument, at a significance level of 0.05. This estimate is based on pre- and post-intervention means and standard deviations from the local dissemination of HEP (Phelan, Williams, Leveile, et al 2002).

Data analysis

We analyzed participant data with paired t-tests for continuous variables and McNemar's test for matched pairs for categorical variables to assess for differences between enrollment and follow-up in their disability risk factors, health and functional status, and hospitalizations.

Results

Participant retention and characteristics

Initial and 12-month follow-up data were available for 115 (51% of the 224) participants whose 12-month follow-ups were due on or before 31 December 2003. Of the remaining 109 (49%) participants who did not provide 1-year follow-up data, one died, 35 (32%) discontinued, 4 (4%) moved away, 9 (8%) graduated before 12 months because their goals were met, 3 (3%) declined to provide data for research purposes, 37 (34%) had some other reason, and 20 (18%) gave no reason. The most frequent reasons listed by the 35 participants who discontinued were "low attendance" (n=19, 54%), "conflicting goals" (n=9, 26%), "health issues resolved" (n=4, 11%), and "illness or injury" (n=3, 9%).

Forty-five (39%) of the 115 participants with one-year follow-up enrolled in the LFP exercise class, and 36 (80%) of those attended more than half of the classes. Nineteen (17%) of the 115 participants with one-year follow-up participated in the CDSM workshop, and 16 (84%) of those attended more than half of the sessions. Data on pairing with a health mentor were not systematically collected.

Table 1 shows selected demographic and health characteristics of participants at the time of enrollment in HEP, comparing completers (those who completed both one

Table 1 Demographic and health characteristics of participants at time of enrollment, comparing those completing one year with those not completing one year

Characteristic	Percent or Mean±SD		p-value
	Completing One Year (n=115)	Not Completing One Year (n=109)	
Age, years, mean±SD	72.8±8.6	71.3±9.7	0.22
Female %	76.5	77.1	0.92
Non-white %	25.0	25.7	0.90
Chronic medical conditions %			
Heart problems	31.0	33.3	0.71
Diabetes	20.4	26.9	0.26
Hypertension	58.4	56.6	0.67
Arthritis	63.7	63.9	0.98
Emphysema	14.2	14.8	0.89
Nervous or emotional	18.6	25.0	0.25
Cataract	53.1	40.7	0.07
Current smoker %	4.4	8.3	0.23
Difficulty with any ADL %	32.7	40.6	0.23
Difficulty with ADL %			
Bathing	20.4	30.2	0.09
Dressing	13.3	23.8	0.05
Toileting	8.0	13.2	0.21
Transferring	17.7	22.6	0.36
Feeding	3.5	5.7	0.45
Difficulty with mobility %			
Climbing one flight	43.4	58.7	0.03
Climbing several flights	70.4	81.4	0.06
Walking one block	32.4	39.2	0.30
Walking several blocks	57.8	63.6	0.39
Blocks walked per week, mean±SD	19±33	31±70	0.13
Disability risk factors			
Depression			
GDS score±SD	3.2±3.2	4.1±3.7	0.05
Physical inactivity			
PACE score±SD	4.9±2.0	4.7±2.2	0.45
Nutritional risk			
DETERMINE score±SD	3.7±2.7	5.1±3.6	0.001

Abbreviations: ADL, activities of daily living; including bathing, dressing, toileting, transferring, and feeding; DETERMINE, disease, eating poorly, tooth loss or mouth pain, economic hardship, reduced social contact, multiple medications, involuntary weight loss or gain, need for assistance in self-care, elderly; Scores ≥4 (range 0–21) on the Nutrition Screening Initiative DETERMINE instrument indicate a greater likelihood of poor health at baseline and functional disability a year later; GDS, 15-item Yesavage Geriatric Depression Scale; scores >5 (range 0–15) suggest depression; SD, standard deviation; PACE, Physician-based Assessment and Counseling for Exercise; scores ≤4 (range 1–11) indicate physical inactivity.

year of the program and the 12-month questionnaire) with non-completers (those who did not complete the 12-month questionnaire). Completers had an average age of 72.8±8.6 years, were mostly women (77%), predominantly white (75%), and averaged 3.5 chronic health conditions (data not shown). Additional analyses (not shown in Table 1) showed no significant differences in the mean number of

chronic conditions (3.6 vs 3.5, $p=0.67$) or in the number hospitalized in the year prior to enrollment (20 vs 19, $p=0.71$) between completers and non-completers. At enrollment, completers reported less difficulty with ADLs, better mobility, and lower severity of disability risk factors compared with non-completers. Physical activity/exercise readiness (PACE) scores did not differ between completers and non-completers.

Disability risk factors

Table 2 shows reductions in numbers of participants with each disability risk factor targeted by HEP and reduction in the severity of each disability risk factor, during one year of HEP participation.

Health status, functional status, and hospitalizations

Table 3 shows the health and functional status and hospitalization of participants at enrollment and after twelve months of participation in HEP. More participants rated their health as good or better at twelve months than initially. The number of participants with one or more bed days and restricted activity days decreased, though not significantly so. There was no change in the number reporting difficulty with either ADLs or mobility. The number of participants

Table 3 Health and functional outcomes and utilization at enrollment and after one year of program participation^a

Outcome	At enrollment variable	At one year follow-up	p-value
Self-rated health, number (%) (n=112)			0.09 ^b
Good, very good, or excellent	77 (69)	87 (78)	
Fair or poor	35 (31)	25 (22)	
Number (%) with ≥ 1 bed day (n=102)	32 (31)	24 (24)	0.13
Number (%) with ≥ 1 restricted activity day (n=104)	48 (46)	35 (34)	0.06
Number (%) any ADL difficulty (n=113)	37 (33)	37 (33)	1.00
Number (%) any mobility difficulty (n=113)	87 (77)	85 (75)	0.82
Number (%) hospitalized (n=107)	19 (18)	19 (18)	1.00
Hospital days, mean \pm SD (n=107)	0.86 \pm 3.0	0.92 \pm 3.1	0.89

Abbreviations: ADL, activities of daily living; SD, standard deviation.

Note: ^aFor persons with complete data at enrollment and follow-up. Numbers vary due to variation in the number of persons who answered each question completely at both enrollment and follow-up; ^bResponses dichotomized by grouping good, very good, or excellent responses together and fair or poor responses together.

hospitalized and the mean number of hospital days did not substantially change from enrollment to twelve months.

Table 2 Number of participants with and severity (mean score) of disability risk factors at enrollment and after one year of program participation^{a,b}

Risk factor	At enrollment	At one year follow-up	p-value
Depression (n=113)			
Number (%)	18 (15.9)	10 (8.8)	0.004
GDS score, mean \pm SD	9.0 \pm 3.2	6.1 \pm 2.8	0.004
Physical inactivity (n=114)			
Number (%)	44 (38.6)	18 (15.8)	0.001
PACE score, mean \pm SD	2.8 \pm 1.0	5.0 \pm 2.2	<0.001
Nutritional risk (n=111)			
Number (%)	49 (44.1)	27 (24.3)	0.001
DETERMINE score, mean \pm SD	6.0 \pm 2.1	5.5 \pm 2.4	<0.001

Abbreviations: ADL, activities of daily living; including bathing, dressing, toileting, transferring, and feeding; DETERMINE, disease, eating poorly, tooth loss or mouth pain, economic hardship, reduced social contact, multiple medications, involuntary weight loss or gain, need for assistance in self-care, elderly; GDS, 15-item Yesavage Geriatric Depression Scale; scores >5 (range 0–15) suggest depression; SD, standard deviation; PACE, Physician-based Assessment and Counseling for Exercise; scores ≤ 4 (range 1–11) indicate physical inactivity.

Note: ^aFor persons with complete data at enrollment and follow-up. Numbers vary due to variation in the number of persons who answered each set of items completely at both enrollment and follow-up; ^bNumber (percent) and mean scores for those with disability risk factor at time of enrollment.

PCP awareness and perceptions of HEP

Questionnaires were returned by 94 PCPs. Of those returning a questionnaire, approximately 60% reported that they were aware of HEP, and about 60% reported that they believed their patients had benefited from participating in the program. About 58% stated that they would recommend HEP to their patients and colleagues, although only about 45% understood the purpose of HEP.

Discussion

Community-dwelling adults who participated in a chronic disease self-management, disability prevention intervention for one year improved their health and reduced their disability risk factors. Specifically, fewer participants were depressed, physically inactive, and/or at nutritional risk after one year of program participation. The number of depressive symptoms declined, the level of physical activity and exercise readiness improved, and nutritional risk diminished for participants who screened positive for these risk factors at enrollment. Self-perceived health improved, fewer

reported any days of restricted activity, and hospitalization did not increase during the year of program participation.

The findings from this five-state dissemination of HEP mirror those from the randomized (efficacy) trial (Leveille et al 1998) in some respects and those from the local dissemination (effectiveness) (Phelan, Williams, Leveille, et al 2002) in other respects. Improvement in three disability risk factors varied among the present and previous dissemination and the randomized trial. Physical activity and exercise readiness (PACE scores) improved significantly in all three studies. Depression improved significantly in both the five-state and the local dissemination, but not in the randomized trial. Nutritional risk improved significantly in the five-state dissemination, but not in either the local dissemination or randomized trial. Perceived health improved in all three studies, significantly only in the local dissemination, marginally in the five-state dissemination, and non-significantly in the randomized trial. Functional decline was prevented or reduced in all three studies, although the bed days measure was significant only in the randomized trial and the restricted activity days measure was marginally significant only in the two dissemination studies. Finally, the percentage of HEP participants hospitalized declined significantly in the efficacy trial (from 21% in the baseline year to 13% at follow-up) but was unchanged in the two dissemination studies. As described previously (Phelan, Williams, Leveille, et al 2002), differing methods have been used over time to ascertain hospitalizations (administrative data for the efficacy trial versus self-report for the present and the local dissemination, the latter of which has been shown by others [Roberts et al 1996; Wallihan et al 1999] to have limited reliability), and thus the present results regarding hospitalizations should be interpreted cautiously.

Two papers describe a program very similar to HEP, called Health Matters, implemented by a California long-term care insurance company in consultation with original HEP staff (Holland et al 2003, 2005; Tidwell et al 2004). A comparison of the Health Matters program and HEP has been published previously (Leveille et al 2004). Similar programs are being tested in other locales with somewhat different populations (Hughes SL and Boulton C, personal communication), and SSSKC is currently in negotiations with Carle Hospital Foundation to include HEP as part of a Medicare demonstration project. These developments all indicate HEP's robust potential for obtaining, for example, capitated funding from Medicare, similar to the Program of All-Inclusive Care for the Elderly for frail elders meeting

nursing home certifiability criteria (Gross et al 2004), or contracts with healthcare insurers whose older members enroll in HEP.

Limitations of the present evaluation include its before-after design, which means that observed results may not be due to the HEP intervention. The other major limitation is that, of 224 participants enrolled, only 115 (51%) completed a 12-month follow-up questionnaire, and thus there was power to detect only large changes on our health and functional outcomes of interest. Such low participation is not unusual for senior center programs in general and is more likely with programs such as HEP, wherein a follow-up questionnaire is requested and no incentive is offered. We observed a similarly high non-completion rate in the local dissemination, which may bias our results. However, our comparison of those who did and did not complete the 12-month questionnaire showed that these groups differed in such a way that effects might have been greater than those observed had the non-completers actually participated in the 12-month follow-up. That is, HEP participants who did not complete the 12-month questionnaire had more ADL difficulty, more mobility difficulty, and greater severity of two of the three disability risk factors at time of enrollment in the program. Based on these differences, one would predict that non-completers would have benefited more than completers had they continued with the intervention, which may have led to greater mean improvement.

In light of the difficulty encountered with retaining participants for one year, and data from the local dissemination suggesting that, among who experience improvement in their disability risk factors, most improvement occurs in the first six months (Phelan, Williams, Wagner, et al 2002), it was decided to change the duration of the program to six, rather than twelve months, with an option for participants to extend for a full twelve months if they desire. This change has been in effect since 2004.

In spite of bias due to dropout, several strengths merit mention. First, the program continued to reach its target population (older adults with chronic conditions at risk for functional decline). Second, the five state dissemination attracted participants who were more diverse than those in the local dissemination (25% vs 11.5% nonwhite, respectively) from a variety of community centers in urban and rural regions of the US. Third, the five state dissemination achieved this enrollment through the cooperative efforts of newly created community-based networks of social service providers, academics, primary

care providers, and healthcare systems. It is important to note that participants reported on herein were not recruited to participate in a study, nor was the program delivered in a controlled study environment. Rather, because this was an evaluation of the effectiveness of a program whose efficacy had been previously established, findings are indicative of outcomes achievable under real world conditions. Fourth, the use of an internet-based data collection and tracking system (WellWare[®]) permitted identification of variations in process or outcomes across the different sites that could be addressed as part of ongoing programmatic quality improvement.

What are the broader implications of the present evaluation? Several issues must be addressed for the HEP program to continue to expand. First, small caseloads were observed in several sites. This phenomenon was likely due to the fact that HEP staff were responsible for developing their own referral base. Though a strong referral base is absolutely essential to ensure adequate program reach, the development of such referral bases needs to be the responsibility of the program administration rather than HEP staff. Second, a great deal of time and effort was expended in order to enroll people of color and refugee/immigrant populations. Many potential participants were found to be in a pre-contemplative stage of readiness for change in health-related behavior, focused on more immediately pressing issues such as economic survival. While such individuals do appear to benefit from HEP participation, they are unlikely to enroll without a physician's encouragement. Therefore, referrals from healthcare providers working in the local community where HEP is offered are essential to ensure program sustainability, and proactive efforts to increase provider awareness of HEP need to be undertaken at the program's organizational level. Finally, several sites had a lengthy start-up period. Analysis of this issue by SSSKC revealed that some sites were not ready to implement HEP. SSSKC has now adopted a business plan for further dissemination of HEP that includes a structured marketing and referral strategy. SSSKC has also partnered with the National Council on Aging to develop a site-readiness assessment instrument that will permit them to determine whether sites with an interest in offering HEP are ready to do so.

In conclusion, the HEP continues to operate and expand under real world conditions, reaching elders at risk for functional decline. Participants who complete one year have a decreased burden of disability risk factors and avoid worsening of health or functional status and increase in

hospitalization. Previous research indicates that under certain conditions, HEP also improves participants' perceived health and function.

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