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Feature Article

Achieving self-management goals among low income older adults with functional limitations

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ABSTRACT

Although self-management interventions can improve symptoms and disease among older adults, there is a dearth of literature on how self-management behaviors may improve factors related to the older adults' physical function. To fill this gap in the literature, we describe the patient-directed self-management goals in nursing visits that relate to physical function as part of a multi-component program. We analyze the self-management goals and outcomes of 367 low- income older adults with functional limitations who participated in the CAPABLE program: a program to reduce the health effects of impaired physical function in low-income older adults. We focus on the following self-management goals that participants chose with the nurses: pain management, depressive symptoms, incontinence, fall prevention, and communication with healthcare providers. The majority of participants chose pain (50%) or fall prevention (51%) as goals and partially or fully met their goals. Improvements across these areas may lead to improved physical function.

Introduction

More than half of U.S. older adults (11 million) live with five or more chronic conditions.[1] They have higher rates of impaired physical function/functional limitations compared to those living without chronic conditions,[1,2] leading to disability, more hospitalizations, and poorer quality of life (QoL) as they age.[3–6] Self-management is vital for improving the health and QoL of aging adults with chronic conditions and may help slow the disability process. Self-management is defined as the collection of tasks performed within the living environment that promote health by addressing conditions or symptoms using five core skills: problem-solving, decision-making, resource utilization, partnerships with healthcare providers, and taking action.[7,8] Although there is extensive literature showing that self-management behaviors are related to improvement in disease and symptoms, there is limited evidence on how self-management can play a role in disablement. Disablement is the process of how a pathology or chronic condition can lead to a path of functional limitations and disability.[2,6,9] This is under-recognized in the self-management literature. Much of the self-management literature focuses on specific chronic conditions rather than on managing downstream consequences of conditions that impair a person's QoL through physical function (e.g., cooking a meal, dressing, and leaving the house). These are important because they interfere with being able to age in place, which most adults prefer.

Together with colleagues, we developed a person-directed, tailored program to address factors associated with physical function among older adults with low- income: Community Aging in Place, Advancing Better Living for Elders (CAPABLE), which is effective in reducing disability.[10,11] The purpose of this current study is the describe the participants' self management goals and the work they did with CAPABLE nurses to achieve these goals. Gaining a deeper insight into this process will help to explain the ways in which nurses can help older adults change behavior and optimize function and physical activity.

Participants chose many different types of goals; however, for purposes of this study, we identified goals that had a relationship with physical function. We hypothesized that exposure to CAPABLE nurse visits would result in goal achievement across five areas related to physical function: pain, depressive symptoms (mood), incontinence, fall prevention, and communication with primary care providers. Although participants worked with both nurses and occupational therapists, the focus of this paper is based only on the goals and strategies that participants

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worked on with the CAPABLE nurses. The outcomes of this paper are the participants' perceptions of their goal achievement. We also examined what strategies the research participants chose to use to work toward meeting their goals and whether they achieved their goals.

Theoretical framework

Although CAPABLE is informed by several theories, the major overarching theory for this analysis is the disablement process framework.[12] In this framework, the trajectory to disability goes from pathology (disease or injury to a body system), to impairments (irregularities in a body system), to functional limitations (restraints in a physical body system that impact the ability to perform a daily task), and ends with disability (loss of ability to perform specific social roles due to chronic disease or impairment).[9,13] This framework stresses that both intrinsic and extrinsic factors modify the disablement process. As demonstrated in Fig. 1, these factors are bi-directional: they can cause or result from functional limitations.[9] CAPABLE was designed to decrease such limitations.

Intrinsic and extrinsic factors

In this study we describe how the CAPABLE nurses actively address both intrinsic factors such as pain and extrinsic factors such as communication with healthcare providers related to physical function that the participants prioritize. Because relationships between physical function and these factors such as pain and depression are bidirectional, addressing them may improve physical function or delay the disablement trajectory. For instance, it is well documented that pain and depressive symptoms are related to poor physical function in older adults, or poor physical function may also lead to more severe pain and depressive symptoms.[5,6,14–18] For instance, Urinary incontinence may develop because of declining physical function and decreased ability to ambulate or toilet.[19] Incontinence may also increase risk of falls, which could lead to poorer physical function.[20] When older adults fall, this may impair their physical function, which further increases their risk of falling.[6,21]

Communicating with healthcare providers is also related to health outcomes.[22,23] Without such communication, physical function may decline or physical decline may even go unnoticed during interactions with providers. Older adults with poor physical function may also have difficulty following prescribed treatment regimens and have higher rates of healthcare utilization, both of which indicate the importance of communication with healthcare providers.[6]

Methods

Design

For this paper, we used data from the treatment arm of two CAPABLE trials: 1) a randomized controlled trial (RCT) funded by the National Institute on Aging (R01- AG040100) and 2) a one-armed trial funded by the Centers for Medicare and Medicaid Services (CMS, 1C1CMS330970) in which all participants received the treatment. This paper is about the process and goal-setting outcomes, we did not include the overall study outcomes. These are presented in other research reports.[11,24]

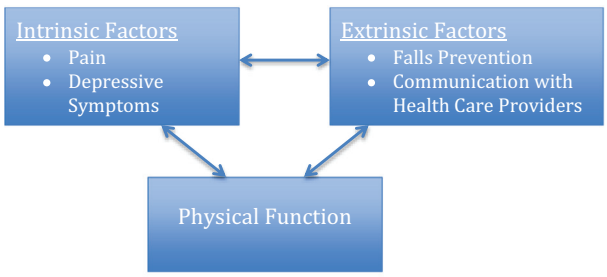

Fig. 1. Physical Function and Related Factors.

Description of CAPABLE

CAPABLE—an interdisciplinary program delivered over 5 months—was developed for low-income older adults who have limitations with activities of daily living, such as bathing and dressing. The program details have been described in previous work.[10,25] CAPABLE is an extension of a successful program called Advancing Better Living for Elders (ABLE), which improved disability, QoL, and reduced mortality risk through a person-directed approach involving occupational therapy, physical therapy, and limited home modifications to help older adults engage in everyday activities of their choice.[5,7] Building on ABLE, CAPABLE added home repair and a nurse component to fully address management of pain, medications, and depressive symptoms, and to help facilitate communication with healthcare providers—all areas that are associated with physical function outcomes within the literature.[5,24,26]

Participants in the CAPABLE program identify and prioritize their areas of strengths and deficits. To achieve their goals (such as getting upstairs to sleep in their own beds rather than the couch), participants identify what they want to work on, such as pain, uneven gait, depressive symptoms, or leg strength. The registered nurses (RN) and occupational therapists (OT) use their discipline-specific knowledge and complex clinical reasoning to engage with the participants' strengths, challenges, goals, and home environment to facilitate self-management that targets their identified goals. The OT in CAPABLE delivers six visits to each client and each visit lasts approximately 60–90 min over a period of five months. The RNs deliver four visits to each client and each visit lasts approximately 60–90 min over a period of five months. This secondary analysis focused solely on the nurse visits, which begin one month after the start of OT visits (with three months left in the program). In these visits, the RN and participant focus on: (1) eliciting goals regarding pain, depression, medication understanding, primary care provider communication, strength and balance; (2) developing an action plan involving tailored strategies that address participant goals; (3) implementing the strategies the participant and RN have developed together.

The RN strategies to work towards goals combine two actions: (1) brainstorming according to a motivational interviewing protocol in which the RN actively listens to the participant to elicit strategies that the participant wants to try, or has tried, and (2) suggesting evidence-based strategies from a pre-developed list. For example, if a participant identifies pain reduction as a prioritized goal, the nurse initiates brainstorming by asking the participant to characterize the pain (e.g. pain rating, pain location, how pain interferes with activities of daily living, current management etc.). Following this, the nurse finds out what the participant has tried and would like to try. Then he or she may suggest other evidence-based strategies including exercising as tolerated, focusing on valued activities, or applying heat, and follow up with the participant's primary care provider as necessary. Strategies chosen by participants are shared during team meetings, and evidence on these proposed strategies are evaluated. In the case of the present study, the authors agreed on how to categorize strategies under specific goals such as heat therapy as a strategy for pain goals.

Eligibility

Participants were low-income adults aged 65 and older who completed the CAPABLE program. Eligibility for participants in both CAPABLE studies were the same with the exception of the definition of low-income. They were all living at home, reporting difficulty in at least one activity of daily living (ADL) or at least two instrumental

activities of daily living (IADL), the ability to stand with or without assistance, and income < 200% of the Federal Poverty Line (NIH RCT study) or income <135% of the Federal Poverty Line (CMS one-armed study).[27] Participants were excluded from either study if they had been hospitalized more than three times in the previous year, were actively receiving cancer treatment, had an expected survival of <1 year, were cognitively impaired, or had plans to relocate within one year of enrolling.

Recruitment

Recruitment for both studies was conducted through a combination of direct mailing of flyers to older adults' homes, word-of-mouth, and referrals from community partners.[28] Both studies were approved by the Johns Hopkins Medicine Institutional Review Board. In Fig. 2, we show the recruitment and attrition of both the RCT and CMS studies. Participants had visits from the same teams of RNs and OTs in each study and the results from each study were the same.[11,29] The final study sample in Fig. 2 was 374; however, for this secondary analysis, we excluded seven participants for whom a proxy answered many of the questions, resulting in a final sample size of 367.

Measures

Sample demographics

The Sociodemographic Questionnaire is a self-report assessment of basic characteristics such as race, age, gender, supplemental health insurance status, and educational level.

Readiness to change

Readiness to change was measured using an algorithm to identify participants' readiness to change.[30] We used the Gitlin and Rose

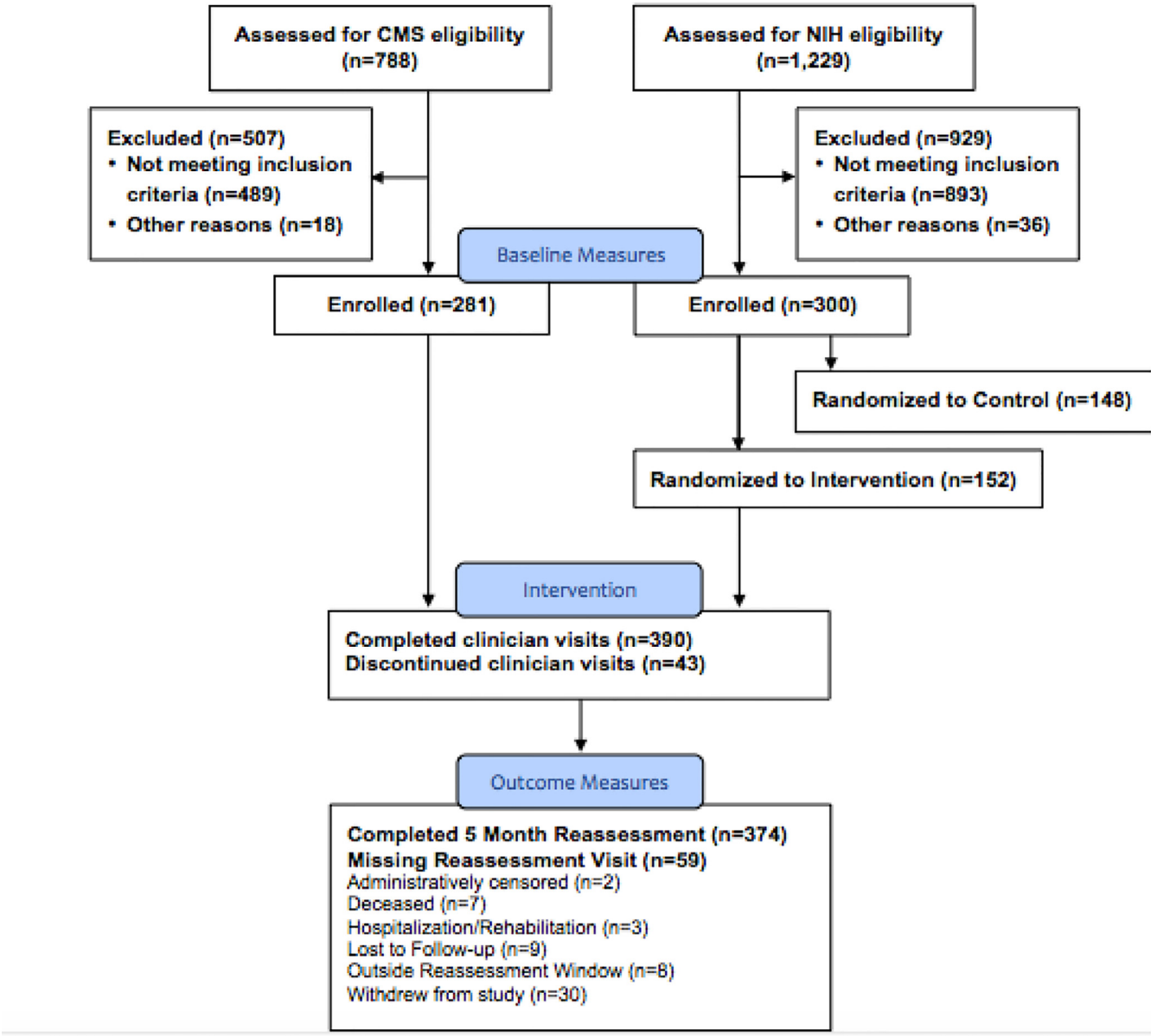

Fig. 2. Combined CAPABLE CONSORT Diagram of Recruitment and Attrition. The final study sample in figure 2 is 374; however, for this secondary analysis we excluded seven participants for whom a proxy answered many of the questions for a final n of 367. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)

rating system,[31–34] which measured readiness to change using four levels according to the transtheoretical readiness to change.[31] These included: level 1- pre-contemplation, level 2- contemplation, level 3- preparation, and level 4- action and maintenance.

Intrinsic and extrinsic factors

Pain: Pain was measured as a component of the EuroQOL-5D,[35] a standardized instrument that measures health-related QoL across five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.[35] Participants reported pain at baseline using three possible pain levels: no pain, moderate pain, or extreme pain. This measure has been used in other studies with low-income older adults.[36]

Depressive symptoms

Depressive symptoms were measured using the Patient Health Questionnaire-9 (PHQ9), which consists of nine items asking about the presence of depressive symptoms.[37] These parallel the nine symptoms of depression described in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition. The PHQ9 has demonstrated strong reliability in older adult populations.[38,39] Scores for this scale range from 0–27, with 27 being the most severe depressive symptoms.

Urinary incontinence, fall prevention, and communication with providers were measured based on participants' self-reports of goal achievement.

Goal achievement

During the first nursing visit, the nurses worked with the participants to set goals. During the last nursing session, the participants self-reported if they fully, partially, or did not meet their stated goals from the first session. Final goal achievement was determined by subjective report from participants.

Data analysis

We used descriptive statistics including mean, standard deviation, and proportion to describe key variables such as pain levels and depressive symptoms. The percentage each of the categories of goals decided upon by participants is described using proportions. We also described the percentages of goals as fully, partially, or not met.

Results

Sample characteristics

The total sample was 79.8% (n = 293) African American and 17.4% (n = 64) non-Hispanic White (see Table 1). The majority of the sample was female at 84.5% (n = 310). At baseline, the mean for depression scores indicated moderate depressive symptoms (mean = 6.87, SD = 5.51) on the Patient Health Questionnaire with a range of 0–27, the entire range of the instrument. Only 12% reported that they had experienced no pain at baseline. About 72% reported moderate pain; 15% reported extreme pain. All participants were below 200% of the Federal poverty line and had an average of 3.9 CEL (range 1–8) for which they reported difficulty. Final goal achievement was not assessed among 4–11% of participants across the different domains. The reason a small percent of goals were not assessed was during the transition from paper to electronic documentation in the beginning phases of CAPABLE some of the goals did not get transferred over.

The percentages of goals met in each category are detailed in Fig. 3.

Table 1
Sample Characteristics.

Characteristic	Statistics
Sample Size (N)	367
Race, n (%)	
White	64 (17.4%)
Black	293 (79.8%)
Hispanic	2 (0.5%)
Asian	4 (1.1%)
American Indian	1 (0.3%)
More than one race	3 (0.8%)
Age, mean (SD)	75.1 (7.43)
Sex, n (%)	
Male	57 (15.5%)
Female	310 (84.5%)
Education, n (%)	
< High School	138 (37.6%)
High School/GED	184 (50.1%)
Bachelor's degree	31 (8.5%)
Master's degree	11 (3.0%)
Doctoral Degree	3 (0.8%)
PHQ-9 Score, mean (SD) Range 0–27 with over 5 indicating mild depressive symptoms	6.87 (5.51)
EuroQOL – Pain Today, n (%)	
No Pain	47 (12.8%)
Moderate Pain	265 (72.2%)
Extreme Pain	55 (15.0%)
Goals chosen by participants, n (%)	
Pain	184 (50%)
Mood/Depressive Symptoms	69 (19%)
Incontinence	56 (15%)
Fall prevention	197(51%)
Communication with Health Care Providers	27 (7%)

Goals and strategies used

Pain

Fifty percent (n = 184) of the participants chose to work on pain as one of their nursing goals. Congruent with the emphasis of the assessment and of the overall program, these pain goals were functional in nature; for example, participants wanted to be in less pain in order "to get up stairs to sleep in their own beds" or "to get dressed by themselves." The self-management strategies that participants identified with their nurses included medication substitution and use at pain onset of heat, prayer, music, distraction/pleasurable activity, and low impact exercises. At the end of the 5-month program, 39% of the participants who chose pain goals reported that they fully achieved the goals, 39% partially achieved their goals, 17% did not achieve their pain goals, and 5% were not assessed on achievement.

Depressive symptoms

Nineteen percent (n = 69) of the participants chose to work on depressive symptoms/mood as one of their nursing goals. Some of the most common self-management strategies that participants selected with their nurses were as follows: to engage in pleasurable events and plan more of them, exercise, manage pain, listen to music, and improve meaningful activity (increase social activity and volunteer). Among participants who chose depressive symptoms/mood goals, 32% fully achieved their goals, 45% partially achieved their goals, 17% did not achieve their mood goals, and 6% were not assessed on achievement.

Incontinence

Among the participants, 15% chose incontinence goals (n = 56). The self-management strategies that participants chose with their nurses to address incontinence goals included Kegel exercises, attention to bladder irritants (caffeine), timed toileting, adjusting diuretics, and posture changes during urination. Among these

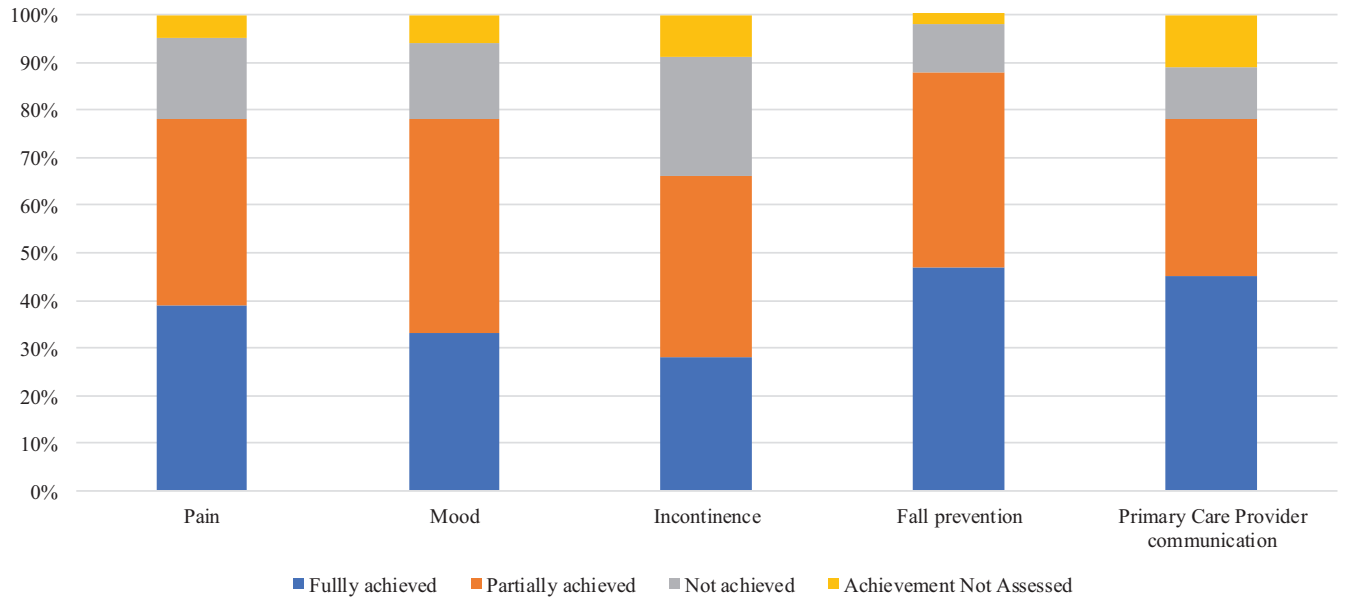

Fig. 3. Percentage of goals met by participants across domains (n = 367).

participants, 29% fully achieved their goals, 38% partially achieved their goals, 25% did not achieve their goals, and 9% were not assessed on achievement.

Fall prevention

Fifty one percent (n = 187) of the participants chose fall prevention goals. The self-management strategies that participants chose with their nurses to work toward fall prevention goals included decreasing dizziness (medication reconciliation, increase water intake), decreasing urgency of going to the bathroom by using Kegel exercises, adjusting timing of diuretics, strengthening core muscles through exercises, and changing positions slowly (e.g., lie to stand). Forty-six percent of the participants achieved their fall prevention goals, 40% partially achieved their goals, 10% did not achieve their goals, and 4% were not assessed on achievement.

Communication with healthcare providers

Seven percent (n = 27) of the participants chose communication/advocacy with primary care provider goals. The self-management strategies that participants with these goals chose included receiving coaching from the nurse to improve advocacy, writing questions in the health passport provided by the RN, and writing questions on the bottom of the medication calendar provided by the RN. In addition, if the participant agreed that it was necessary, the nurses corresponded with the primary care provider office by letter or phone calls.[40] Among these participants, 44% fully achieved their goals, 33% partially achieved their goals, 11% did not achieve their goals, and 11% were not assessed on achievement.

Discussion

In this analysis of self-management goals related to function among low- income older adults, the participants chose pain and fall prevention goals most frequently. The least chosen goal category was communication with primary care providers. Of the goals chosen, participants perceived they met the fall prevention goal most often. Managing pain was also a strategy that was used to improve mood. With the exception of mood, we learned that some form of exercise was a strategy used across all goal categories. These self-management goals were participant-directed and focused on the individual strengths and deficits of the participants.

This secondary analysis highlights the importance of using person-directed goal setting to encourage health promotion and lead to better outcomes among low-income older adults. This study aligns with research that has demonstrated the effectiveness of goal setting among populations with low-income and older adults.[41–44] Using a person-directed model may lead to long-term behavioral changes and attainment of goals. In addition, while it is essential to use objective measurements to show the effects of person-directed self-management interventions, the participants' goal attainment is also crucial. When participants can see change and are able to achieve their own goals, this may enhance their motivation, health promotion behaviors, and long-term outcomes.

The nurse visits in CAPABLE played a part in assisting participants to meet their goals by helping set, implement, and assess them. The brainstorming process allows participants to list all possible strategies available to achieve an identified goal. Following this, participants are able to prioritize known strategies; discard those that were ineffective, continue effective strategies, and seek new strategies from the nurse. Researchers have reported successful outcomes when using nurses in self-management interventions;[45] however, there is a need for more self-management interventions that use nurses.

This work has important implications for practice, research, and policy within nursing. This analysis builds on the existing literature in implementing a patient-directed self-management program. Future self-management studies could benefit from addressing factors related to physical function among low-income older adults and aging minorities. Last, for a variety of reasons, including limited time and reimbursement incentives, clinicians currently often focus solely on patient self-management of medical issues to the exclusion of functional needs. This analysis shows it is possible to address both. Nurse research should provide the needed evidence and expertise to ensure that policies include the functional needs of our aging population.

Limitations

One of the limitations of this study is that it is difficult to determine which strategies were the most effective in helping participants achieve their self-management goals; for instance, was heat alleviating pain more than the process of safely getting into the bath? There were potential issues related to pooling data from two trials for this particular study given their different inclusion criteria on poverty. However, the

demographics were equivalent in the two trials. Another limitation is that nurses who had an established rapport with participants collected data on the outcomes of goals; therefore, participants may have altered responses based on social desirability. In future studies, we may compare the reported goal achievements with the outcomes measures.

Strengths

There were several strengths of this study. Our sample was low-income older adults who were also mostly African Americans, which are both understudied groups who often experience both higher healthcare utilization and health disparities across many health indicators.[46–48] The study also focused on meeting goals in more than one area, such pain, falls, incontinence, etc. This is an important strength because multiple health outcomes may be addressed simultaneously.

Conclusion

In this study we identified that a self-management intervention can assist older adults with meeting goals in surrounding factors that have relationships with physical function including pain, depressive symptoms, incontinence, fall prevention, and communication with healthcare providers. An improvement across these areas may lead to improved physical function among older adults. These are important findings for nurse researchers and clinicians alike. With a changing healthcare system and unequal levels of access across our older adult populations, self-management is a way for older adults to engage in improving their health and overall physical function.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.gerinurse.2019.01.003.

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