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A Community-Partnered, Evidence-based Approach to Improving Cancer Care Delivery for Low-income and Minority Patients with Cancer.

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Abstract

Introduction: Community-engaged adaptations of evidence-based interventions are needed to improve cancer care delivery for low-income and minority populations with cancer. The objective of this study was to adapt an intervention to improve end-of-life cancer care delivery using a community-partnered approach.

Methods: We used a two-step formative research process to adapt the evidence-based *Lay health workers Educate Engage Encourage Patients to Share* (LEAPS) cancer care intervention. The first step involved obtaining a series of adaptations through focus groups with 15 patients, 12 caregivers, and 6 leaders and staff of the Unite Here Health (UHH) payer organization, and 12 primary care and oncology care providers. Focus group discussions were recorded, transcribed, and analyzed using the constant comparative method of qualitative analysis. The second step involved finalization of adaptations from a community advisory board comprised of 4 patients, 2 caregivers, 4 oncology providers, 2 lay health workers and 4 UHH healthcare payer staff and executive leaders.

Results: Using this community-engaged approach, stakeholders identified critical barriers and solutions to intervention delivery which included: 1) expanding the intervention to ensure patient recruitment; 2) including caregivers; 3) regular communication between UHH staff, primary care and oncology providers; and 4) selecting outcomes that reflect patient-reported quality of life.

Conclusions: This systematic and community-partnered approach to adapt an end-of-life cancer care intervention strengthened this existing intervention to promote the needs and preferences of

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patients, caregivers, providers, and healthcare payer leaders. This approach can be used to address cancer care delivery for low-income and minority patients with cancer.

Keywords

Community-engaged adaptation; cancer care delivery; low-income and minority populations; end-of-life; community care

Introduction

Despite decreases in national cancer death rates [1], cancer mortality remains disproportionately high among racial and ethnic minorities [2–4] and patients from low socioeconomic status backgrounds [2,5]. At the end-of-life, minority and patients with low-income experience higher rates of unwanted acute care utilization [6–8] and undertreated symptoms [9,10], lower satisfaction with care [11,12], fewer discussions with their healthcare providers regarding their end-of-life care preferences [13–16], and lower hospice use [17,18] as compared to non-Hispanic white patients and those with higher income. While communication between patients and their healthcare providers regarding prognosis, end-of-life care preferences, and symptom management can significantly improve care at the end-of-life [19,20], barriers persist in ensuring equitable access to these important end-of-life cancer care services [13,21,22]. These barriers include communication challenges between patients and their healthcare providers [23,24], inadequate healthcare provider time during clinic visits [24,25], and lack of infrastructure [24] to support the provision of these crucial services.

Several interventions utilize lay personnel to improve care delivery for low-income and minority patients [26–29]. Despite the effectiveness of lay health workers (LHWs) assisting with the delivery of preventive cancer care services, few interventions utilize lay personnel to assist with the delivery of end-of-life cancer care services [30,31]. Previously, we designed and conducted a randomized trial at one Veterans Affairs facility to test the effect of utilizing a LHW to assist patients with discussing their end-of-life care preferences with their oncology care teams [30]. The intervention improved patient experiences with their cancer care, reduced unwanted end-of-life acute care utilization, and decreased costs of care for Veterans with advanced stages of cancer as compared to usual cancer care [30]. Evidence lacks, however, regarding whether this intervention can be adapted and tested for patients with cancer in community settings. To ensure that interventions are adapted to reflect community preferences, direct engagement of patients, healthcare providers, and other key stakeholders is fundamental [32,33]. In this paper, we describe a community-partnered approach to adapt the LHW goals of care intervention for low-income and minority patients with cancer in the community. Specifically, we: 1) identified specific barriers and potential solutions to improving cancer care delivery at the end-of-life and 2) adapted a previously developed intervention to meet the needs of the patients and the healthcare delivery organization characteristics.

Methods

Our community partner was the Unite Here Health (UHH) labor union organization. UHH is a non-profit, multi-employer Taft-Hartley Trust Fund governed by a Board of Trustees composed of union and employer representatives with a mission “to provide health benefits that offer high-quality, affordable healthcare to our participants at better value with better service than is otherwise available in the market.” UHH serves 250,000 mostly non-white (87.5%) hourly-wage workers with household incomes less than 200% of the Federal Poverty Line (99%) who are employed by U.S. hospitality, food service, and gaming industries [10]. Community-based primary care and oncologists provide clinical care for UHH beneficiaries through either fee-for-service or annually negotiated contract arrangements.

We used a pragmatic application of the RE-AIM framework [34] to guide the adaptation (Table 1). The goal was to adapt components of the lay health worker end-of-life cancer care intervention to meet the specific needs of major stakeholder groups in Chicago, IL and Atlantic City, NJ that included: 1) patients and their caregivers who are members of UHH; 2) community-based primary care and oncology providers who deliver clinical care to UHH beneficiaries; and, 3) UHH executive leadership and staff.

The first stage of the adaptation included focus groups with patients, caregivers, oncology providers, primary care providers, palliative care providers, UHH lay health workers, UHH staff, and the UHH executive leadership. The second stage included presentation of the adapted intervention to a UHH community advisory board (CAB) (comprised of UHH beneficiaries with cancer, caregivers of UHH beneficiaries with cancer, lay health workers, oncology and primary care providers, and UHH staff and executive leaders) and making a second round of adaptations based on their input.

In the first stage, we developed questions based on the Re-Aim framework to guide focus group discussions on barriers to intervention delivery and solutions to adapt the intervention (Table 1). An experienced moderator conducted seven focus groups (6–8 participants per group) that lasted approximately 1 hour each. Two focus groups were conducted with patients (n=16), two focus groups with caregivers (n=12), two with oncology, primary care, and palliative care providers who provide cancer care services for UHH beneficiaries (n=12), and one with UHH staff and executive leaders (n=6). Focus groups among patients and caregivers were restricted to patients who had been diagnosed for at least 3 months to ensure adequate experience with the way cancer care is delivered. One of the patient focus groups was conducted in Spanish. Focus groups with providers included one focus group comprised of physicians (n=4) and nurses (n=2) and a second focus group comprised of UHH lay health workers (n=3), UHH social worker (n=1), and UHH case managers (n=2). One focus group with UHH leaders included union leaders (n=2), the UHH national medical director (n=1), two UHH site medical directors (n=2), the UHH patient experience leader, and a UHH claims analyst (n=1). We audiotaped, transcribed, and translated the Spanish patient focus group into a qualitative data management software. Two qualitative coders read the first transcript and created codes and, through an iterative process, developed the codebook, and independently coded each transcript. Discrepancies in coding were discussed

and first author (MP) made modifications to the codebook. Cohen's kappa scores,[35] to measure consistency between coders, were 87–91%, suggesting excellent consistency.[36] For the 3,121 unique quotations, the investigator team conducted thematic analysis based in grounded theory and performed using the constant comparative method of qualitative analysis [37].

In the second stage, following the focus groups, a Community Advisory Board (CAB) comprised of 16 individuals (4 patients, 2 caregivers, 4 oncology providers, 2 lay health workers and 4 UHH staff and executive leaders) adapted the intervention components over a series of 4 total bi-weekly in-person meetings. All participants in the study provided informed consent prior to study procedures. The study was reviewed and approved by the Stanford University Institutional Review Board.

Results

Phase 1: Stakeholder Focus Groups

Among patient and caregiver focus group participants, 53% were female, 37.5% self-reported as Hispanic or Latino, 6.25% as American Indian/Alaskan Native, 18.75% as Asian, 25% as black, and 12.5% as white. Focus groups with providers, UHH staff, and leadership, included 30% who self-reported as Hispanic or Latino, 15% as Asian, 15% as black, 20% as white, and 20% as more than one race. Table 2 lists the major themes that emerged from the focus groups that are relevant to intervention adaptation. Stakeholders identified critical barriers to intervention delivery. Identified barriers included: 1) patient recruitment and retention; 2) attention to caregiver needs; 3) communication between the UHH staff and community clinical primary care and oncology providers; and 4) outcomes that reflect the goals of the intervention and mission of the stakeholder groups to improve cancer care delivery. Based on these themes, the most important adaptations suggested from input across all stakeholder focus groups included: 1) language-specific promotional materials to encourage recruitment and retention in the intervention; 2) inclusion of caregivers in some intervention components; 3) regularly scheduled meetings among team members at UHH, providers, and leadership to connect stakeholders and enhance program goals. Across all stakeholder groups, recommendations were to tailor alternative formats for intervention delivery based on patient-preference. Suggestions included providing telephone-based intervention delivery for goals of care discussions and symptom assessments.

Phase 2: Community Advisory Board

The CAB discussed several key adaptations to the intervention based on critical issues identified by focus group participants in Phase 1.

Adaptation #1: Encourage intervention recruitment by: a) providing language-specific promotional materials when UHH members register; b) providing follow-up detailed information to UHH members after a cancer diagnosis; c) changing the intervention name and d) expanding intervention inclusion criteria.

CAB members suggested providing intervention promotional materials at the time UHH members enroll in UHH benefits. CAB members agreed that early introduction to this program at the time of enrollment in UHH, similar to promotional materials provided regarding diabetes management, would help to normalize the program for all members as one of a wide array of services offered by UHH for its beneficiaries. Early promotion of these services would help to remove any stigma attached to the intervention. CAB members felt that these materials would also encourage early awareness and facilitate increased use of these services among UHH beneficiaries. CAB members also suggested providing follow-up, tailored and detailed information about the intervention when UHH beneficiaries are diagnosed with cancer to remind them of this service. They suggested providing all beneficiaries, after a cancer diagnosis, with a step-by-step explanation of the intervention and a follow-up telephone call by one of the LHWs to encourage enrollment in the intervention. To further enhance recruitment to the intervention, CAB members chose to name the intervention the “Lay health workers Educate, Engage, and Encourage Patients to Share (LEAPS) program” and expanded inclusion criteria to include all stages of disease instead of only those diagnosed with advanced stages.

Adaptation #2: Engage caregivers in the intervention through support groups and obtain and include caregiver feedback to enhance the intervention’s effectiveness.

CAB members agreed that caregivers should be incorporated into the intervention given the concerns raised by focus group members. CAB members suggested offering caregiver support groups and promoting this service for caregivers when members enroll in UHH. CAB members also suggested sending follow-up materials to eligible beneficiaries after a new cancer diagnosis to encourage caregiver participation. They wanted to include caregivers in the evaluation process through one-on-one interviews with caregivers at key time points during the intervention, including 6-months after intervention enrollment and again upon beneficiaries’ death. CAB members felt that by obtaining feedback from caregivers, additional services could be offered by UHH to support caregivers’ specific needs.

Adaptation #3: Encourage routine communication among the care teams through: a) regularly scheduled meetings to connect lay health workers, UHH staff and leadership, and primary care and oncology clinicians; b) regularly scheduled bi-annual educational sessions for lay health workers; and c) weekly case rounds.

The CAB suggested three strategies to enhance communication between all key stakeholders. These included: 1) monthly meetings among lay health workers, UHH staff, primary care and oncology clinicians; 2) bi-annual educational sessions for lay health workers; and, 3) weekly case rounds. Monthly conferences for lay health workers, UHH case managers, UHH nurses, UHH leadership, and primary care and oncology clinicians were suggested as a way to discuss intervention implementation changes. These monthly meetings would be discussion-based and would cover specific items such as intervention goals and progress and changes to implementation that may enhance the intervention’s effectiveness and reach.

Bi-annual educational sessions for lay health workers were suggested to increase the comfort of LHWs with commonly encountered topics regarding advance care planning and cancer symptom management. All UHH staff and primary care and oncology clinicians would be invited to attend. These hour-long topic-based webinars would provide a presentation on the management of a wide array of issues that the LHW may face and would allow ample opportunity for discussion and questions. For example, these sessions may include addressing symptoms from newly approved U.S. Food and Drug Administration cancer therapeutics.

Weekly case rounds were designed to provide another setting for LHWs to discuss shared patients and to increase communication with UHH staff and leadership and primary and oncology care providers. These case rounds were designed to allow the LHW to discuss the care and management of shared patients with the primary care and oncology clinicians and UHH team.

Adaptation #4: Process and evaluation outcomes to match values of the patients, their caregivers, and the UHH organization.

The CAB suggested several ways to measure the impact of the intervention on UHH beneficiaries with cancer and their families. First, CAB members suggested that the primary outcome of the intervention should focus on patient-reported outcomes such as quality of life and patient activation. CAB members also suggested that secondary outcomes should include metrics that would help to understand the financial impact of the innovation such as healthcare utilization and total costs of care. CAB members suggested that these outcomes would help to plan for dissemination of the intervention to other UHH sites. CAB members also suggested that UHH invest in a shared electronic platform to track process metrics and intervention activities, such as dates of goals of care conversation and the number and dates of patient contacts made by the lay health worker.

Discussion:

The Lay health workers Educate, Engage, and Encourage Patients to Share (LEAPS) intervention was adapted, using a community and patient-engaged approach, to meet specific needs of UHH patients, their caregivers, healthcare providers, and the UHH healthcare benefit payer organization. We found that the intervention's objective, as previously designed and tested [38,30], was congruent with key community stakeholder values. In our two-phase adaptation process, we identified specific opportunities to tailor the intervention for the UHH community and its healthcare providers. The final adaptations addressed major gaps in cancer care delivery for UHH patients, including accrual and retention of patients with cancer in the intervention, inclusion of caregivers, and communication between UHH personnel and community-based primary and oncology care provider teams.

This study fills a critical gap in research aimed at tailoring multi-level cancer-focused interventions for patients, caregivers, healthcare providers, and payer organizations in oncology. Given increasing support for policy changes to provide improved quality cancer care for patients [39], adaptation of effective interventions to meet community needs is

critical to reduce disparities in cancer care delivery [40]. In this study, we directly engaged patients, caregivers, and key stakeholders to adapt the evidence-based LEAPS intervention to reflect the cultural preferences of the UHH community based on an adapted RE-AIM framework [34].

Similar to previously described adaptations of behavioral interventions, the adaptations recommended through this process included intervention promotion [41], expansion of intervention eligibility both for patients and caregivers [42], and consideration of outcomes that specifically address the community's needs and values [43]. However, other common adaptations, such as provision of educational materials for patients with limited health literacy [44,45] and utilization of oncology clinics and professional personnel to deliver some of the intervention components [46,45] were not suggested. It is possible that many of these adaptations were not suggested given the infrastructure of UHH. For example, UHH routinely modifies all health educational materials at a fifth grade reading level and all current benefit services such as diabetes management and tobacco cessation are delivered by lay personnel in the UHH benefits offices. Additionally, all participants in the focus groups and CAB were highly supportive of using trained lay personnel and suggested that shared understanding of social contexts would enhance the effectiveness of the cancer intervention if delivered by a lay health worker.

This study has some limitations. First, the adaptations suggested by the key stakeholders in this study may not generalize to other community settings as the adaptations were designed to meet the needs of the UHH community. Furthermore, although we obtained responses from diverse participants, it is possible that subgroups of participants may differ in their perspectives on the adaptations that were suggested. For example, many of our patient and caregiver focus group participants were foreign-born. Although we purposively selected patient and caregiver focus groups based on race/ethnicity, age, and gender, our small sample size precludes summarizing the adaptations suggested based on these demographic characteristics, and, therefore the intervention may need to be adopted for specific subgroups such as US-born minority populations. During implementation of the intervention, UHH can undertake additional tailoring to customize the intervention for specific subgroups if this poses an issue.

In conclusion, our systematic and community-engaged approach to tailoring an effective intervention for the UHH is a feasible way to engage stakeholders directly in the research process. This evidence-based intervention adaptation process has potential for wide-spread applicability to the adaptation of other evidence-based interventions among patients with cancer. A planned pilot test of the adapted intervention will provide insight on the effectiveness of this intervention among low-income and minority UHH beneficiaries receiving cancer care in two UHH community settings.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1:

Focus Group Discussion Questions based on the RE-AIM Framework

RE-AIM Dimension	Description	Questions to Guide Focus Group Discussions
REACH	Facilitators and Barriers to ensuring access to high quality cancer care	<ul style="list-style-type: none"> • What can we do to attract our target audience? • How do we package and adapt the intervention to ensure willingness to participate when it is offered?
EFFECTIVENESS	Potential to improve end-of-life cancer care disparities	<ul style="list-style-type: none"> • What can we do to improve the likelihood of effectiveness of the intervention? • What outcomes should we measure to ensure success for specific populations?
ADOPTION	Facilitators and barriers of adopting the adapted intervention	<ul style="list-style-type: none"> • For what settings should we adapt the intervention? • How do we package and adapt the intervention to maximize willingness of settings and staff to include the intervention as something they do in regular practice?
IMPLEMENTATION	Resources required, delivery format of intervention components, facilitators and barriers to implementation	<ul style="list-style-type: none"> • What would make it easier for settings and staff to deliver the intervention? • What would make it difficult for settings and staff to deliver the intervention?
MAINTENANCE	Facilitators and Barriers of Sustainability	<ul style="list-style-type: none"> • How do we facilitate long-term behavior change among all stakeholders? • What ongoing support do we need to include to enable all stakeholders to continue to apply the intervention content?

Table 2: Intervention Adaptations based on the RE-AIM Framework by Stakeholder group

RE-AIM Dimension	Stakeholder Group	Feedback	Intervention Adaptations
REACH	Patients	<ul style="list-style-type: none"> • Tailor educational materials • Use social media to promote 	<ul style="list-style-type: none"> • Language-specific educational materials including introduction packets at UHH registration, language-specific advance directives and goals of care documents • Use Facebook page and website to promote intervention
	Caregivers	<ul style="list-style-type: none"> • Invite caregivers to participate • Provide support groups • Use testimonials of patients to encourage others to participate 	<ul style="list-style-type: none"> • Caregiver support groups • Intervention components to also incorporate caregivers specifically regarding education of goals of care and ways to support symptom management
	Providers	<ul style="list-style-type: none"> • Provide one point of contact for the intervention • Find a good name for the intervention • Provide opportunities for participants to engage with one another 	<ul style="list-style-type: none"> • Identify one UHH champion at each site to contact one nurse champion at each oncology practice • Intervention name: Lay Health Workers Educate, Engage, and Activate Patients to Share (LEAPS) • Provide caregiver support groups • Ongoing monthly team meetings • Create weekly lay health worker and UHH nurses and case manager meetings at each site
EFFECTIVENESS	Staff	<ul style="list-style-type: none"> • Encourage all beneficiaries to participate regardless of stage of disease • Use UHH registration to promote the intervention 	<ul style="list-style-type: none"> • Include all stages of disease • Provide information packet at time of UHH registration
	Patients	<ul style="list-style-type: none"> • Measure activation. • Focus on quality of life 	<ul style="list-style-type: none"> • Measure change in quality of life as the primary outcome • Assess patient activation measure on each patient
	Caregivers	<ul style="list-style-type: none"> • Measure caregiver distress • Provide opportunities for caregivers to discuss experiences 	<ul style="list-style-type: none"> • Conduct bereaved caregiver interviews • Incorporate caregiver support groups
ADOPTION	Providers	<ul style="list-style-type: none"> • Collect process metrics that include how the intervention may impact provider time, number of contacts with patients, and number of contacts between UHH staff and oncology providers regarding patients in the intervention • Collect patient satisfaction with oncology care 	<ul style="list-style-type: none"> • Include tracking of process metrics • Collect patient experiences with cancer care providers
	Staff	<ul style="list-style-type: none"> • Include patient and their caregiver experiences • Include measures that can impact budget requirements for the intervention (include total costs of care, healthcare use.) 	<ul style="list-style-type: none"> • Secondary outcomes to incorporate total costs and healthcare use data. • Conduct patient and caregiver interviews to measure experiences.
	Patients	<ul style="list-style-type: none"> • Provide patient testimonials to other patients and to providers. 	<ul style="list-style-type: none"> • Encourage participants to provide testimonials regarding program experience • Incorporate patient interviews into the evaluation
	Caregivers	<ul style="list-style-type: none"> • Provide caregiver feedback regarding successful and unsuccessful aspects of the intervention 	<ul style="list-style-type: none"> • Include caregiver interviews into the evaluation
	Providers	<ul style="list-style-type: none"> • Create engagement among all providers to discuss the intervention on an ongoing basis • Engage other home-based agencies • Consistent and ongoing training and support for providers • Identify a champion at each site 	<ul style="list-style-type: none"> • Monthly project working group meetings to encourage discussion regarding intervention components, • Quarterly training among all providers • Bi-annual training for lay health workers • Incorporate home-health agencies and local hospice agencies to participate

RE-AIM Dimension	Stakeholder Group	Feedback	Intervention Adaptations
	Staff	<ul style="list-style-type: none"> • Provide ongoing feedback of intervention success to the union leaders and national medical director • Consistent and ongoing training to providers and lay health workers • Ensure the intervention is feasible to deliver across all settings by including common equipment (e.g., documentation resources for the lay health workers such as an electronic platform that is accessible across sites and standardized and standardized enrollment procedures) 	<ul style="list-style-type: none"> • Collect and evaluate metrics of intervention success at routine intervals • Disseminate intervention results bi-annually to UHH leadership • Invest in a documentation platform standardized across UHH sites
IMPLEMENTATION	Patients	<ul style="list-style-type: none"> • Blend the format for delivery of services such as telephonic delivery of intervention and home visits • Tailored delivery of services based on patient preferences for communication of the services 	<ul style="list-style-type: none"> • Incorporate patient preferences for delivery of intervention components. • Incorporate home visits
	Caregivers	<ul style="list-style-type: none"> • Telephonic or internet delivery of intervention • Need acute care transition interventions • Provide caregivers input to the lay health workers routinely 	<ul style="list-style-type: none"> • Incorporate acute care transition intervention components • Incorporate caregivers in the intervention at time of patient involvement with lay health workers and through routine intervals to assess caregiver input
	Providers	<ul style="list-style-type: none"> • Ensure access to documentation of encounters with patients and caregivers between all providers • Weekly contact between UHH point of contact and provider point of contact to discuss patient cases • Incorporate ways to ensure fidelity to the intervention • Provide space to conduct the intervention 	<ul style="list-style-type: none"> • Weekly report of patient cases with daily report if urgent • Protocol for intervention delivery with manual of training resources. • Provide space for intervention delivery in UHH union offices and UHH care centers
	Staff	<ul style="list-style-type: none"> • Conduct weekly case presentations to discuss ongoing cases • Make sure there is an ongoing team approach to the intervention delivery • Carefully consider funding considerations and how to get buy-in from all stakeholders routinely 	<ul style="list-style-type: none"> • Create a weekly case presentation seminar open to all members of the care team • Conduct monthly project working group meetings to discuss goals and encourage ongoing team-based approach • Incorporate bi-annual presentation of intervention successes to the UHH leadership
MAINTENANCE	Patients	<ul style="list-style-type: none"> • Branding and promotion of the intervention at time of registration into UHH before cancer diagnosis may be important 	<ul style="list-style-type: none"> • Create a new name such as Lay Health Workers engage, Encourage, and Activate Patients to Share (LEAPS) • Incorporate promotion materials at time of UHH beneficiary registration
	Caregivers	<ul style="list-style-type: none"> • Use of ongoing contact with small reminders, phone calls, emails and encourage caregivers to support long-term maintenance 	<ul style="list-style-type: none"> • Provide newsletter to families and beneficiaries that highlight the program • Incorporate caregiver support to encourage long-term commitment to program by members
	Providers	<ul style="list-style-type: none"> • Keep providers motivated and engaged • Certification for the lay health workers • Annual refresher trainings 	<ul style="list-style-type: none"> • Bi-annual webinar series to keep providers encouraged • Monthly Project Working Group meetings to ensure engagement • Annual refresher trainings for lay health workers
	Staff	<ul style="list-style-type: none"> • Collect cost-benefit of the intervention for policy changes inside and outside of the organization • Continue to provide funding, provider and patient support 	<ul style="list-style-type: none"> • Ongoing collection of important outcome metrics to determine budget impact analysis • Ensure funding for stakeholder support through routine bi-annual presentations to the UHH leadership